

Appendix C

Wisconsin Dementia and Aggressive/Abusive Behavior Summit Background Paper

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Summit Background Paper

Table of Contents

| | |
|---|----|
| Introduction..... | 1 |
| Why are we doing this? | 1 |
| Scope of the project | 2 |
| Prevalence of abuse and aggressive behavior..... | 3 |
| The experience of Alzheimer’s disease..... | 5 |
| The caregiving experience..... | 5 |
| Who caregivers are..... | 5 |
| The overall experience..... | 6 |
| Caregiver stress..... | 8 |
| Depression | 9 |
| Ambiguous loss..... | 9 |
| Caregiver coping with problematic behaviors | 10 |
| Caregiver assessment of care receiver | 13 |
| Executive function | 14 |
| Family dynamics..... | 15 |
| Past trauma | 15 |
| Displaced aggression | 15 |
| Unclear boundaries..... | 16 |
| Domestic violence | 16 |
| “Benign” causes of aggressive/agitated behavior by person with Alzheimer’s disease .. | 17 |
| Environmental strains | 17 |
| Sensory overload..... | 17 |
| Interpersonal strains..... | 18 |
| Fear and escalation..... | 18 |
| Medical conditions | 18 |
| Depression and other mental illnesses..... | 19 |
| Post traumatic stress disorder (PTSD) and past traumas | 19 |
| Abusive caregivers | 21 |
| Typology of abusers..... | 21 |
| Retaliation..... | 23 |
| Assessing situations of aggression and abuse..... | 23 |
| Assessing caregivers | 24 |
| Assessing relationships..... | 24 |
| Assessing persons with Alzheimer’s disease | 24 |
| Interviewing collaterals | 25 |
| Medical and psychological exams | 25 |
| Assessment instruments | 26 |
| Mini Mental Status Exam (MMSE)..... | 26 |
| Behavioral Dyscontrol Scale (BDS)..... | 26 |
| Problem Behavior Inventory (PBI) | 26 |

| | |
|--|----|
| Neuropsychiatric Inventory Questionnaire | 27 |
| Columbia University Scale for Psychopathology in AD..... | 27 |
| Boundary Ambiguity Scale | 27 |
| Pearlin's Mastery Scale | 27 |
| Behavior Profile and Behavior Observation Forms | 27 |
| Cornell Scale of Depression in Dementia (CSDD) | 27 |
| Intervening | 27 |
| Addressing Alzheimer's disease behavioral problems | 28 |
| Addressing caregiver stress | 30 |
| Educating caregivers..... | 30 |
| Caregiver support groups..... | 30 |
| Changing perception..... | 30 |
| Self-help books | 31 |
| Enrich the caregiving experience | 31 |
| Shifting the caring dyad | 32 |
| Redefine the behavior as activity..... | 32 |
| Validation Therapy..... | 32 |
| Change the environment | 33 |
| Addressing abuse | 33 |
| Plan for safety | 33 |
| Think about double victims | 34 |
| Watch for victim-blaming and self-blaming | 34 |
| Make sure other professionals know what they need to know..... | 35 |
| Sexuality, sexual abuse and assault, and consent issues..... | 35 |
| Ability to consent to sexual activity..... | 36 |
| Sexual abuse..... | 36 |
| Sexually inappropriate behavior | 37 |
| Dementia Response Teams | 37 |
| Meshing perspectives | 37 |
| Specific professions' needs | 39 |
| Training topics..... | 40 |
| Consultation model of training | 40 |
| System issues | 40 |
| Responsibility..... | 41 |
| Prioritization..... | 41 |
| Advocacy..... | 41 |
| Legal barriers | 41 |
| Funding | 41 |
| Lack of batterers' treatment programs | 42 |
| Questions for later | 42 |
| Bibliography | 44 |
| Appendix A: Level One Work-up | 49 |
| Appendix B: Mini-Mental Status Exam | 51 |
| Appendix C: Behavioral Dyscontrol Scale..... | 53 |
| Appendix D: Problem Behavior Inventory..... | 56 |

Introduction

The Administration on Aging awarded Wisconsin's Department of Health and Family Services, Division of Supportive Living, Bureau of Aging and Long Term Care Resources (BALTCR) a three-year Alzheimer's Disease Demonstration Grant in 2000. A specific issue to be addressed during the grant period is the identification of protocols and appropriate interventions for persons with Alzheimer's disease experiencing aggression or abuse and troublesome outcomes because of these experiences. These protocols will be used by community-based dementia response teams (DRTs).

That's our mandate. The process for getting there involves gathering about 40 experts from a wide variety of professions and experiences, and, through their discussions, developing a ground-breaking synthesis of what we think can be done in these situations.

There is a wide range of questions we'll need to address. Summit participant Betsy Abramson¹ listed just a few of them:

- What do the dementia response teams need to be trained on?
- Where's a safe place to put someone who has dementia and is aggressive?
- Where is a safe place for the person who has been hurt or harmed?
- How can the needs of the victim be addressed, especially when there is a possibility of removing the aggressor, who can also be the care provider?
- How do we keep relationships intact while at the same time getting the victim and the aggressor care, services, and protection?
- What role do elder abuse interdisciplinary teams play in these situations? How are DRTs similar to or different from our more traditional I-teams and Coordinated Community Response Councils?
- Given that law enforcement gets one hour of training on dementia, how can we best/most effectively use that training time?
- What are the best ways to train people in different disciplines?
- How are courts going to be involved?

To help us address these and many other questions, this paper was developed. Approximately 50 key articles and books representing various perspectives on the issue were reviewed. Many of these articles and books were recommended by Summit participants. Most of the Summit participants were also interviewed. This compilation of ideas is a starting point for the Summit discussions.

Why are we doing this?

Many studies show that most elders would prefer to remain in their own homes, sometimes up to and including dying there. In addition, many families wish to keep their

¹ Unless otherwise noted, all comments attributed to Summit participants come from interviews conducted in April and May, 2002, to gather input for this paper.

loved one with them. Unfortunately, both wishes are challenged by the reality of the progressive, debilitating nature of Alzheimer's disease. As many as 90% of patients with dementia reportedly become institutionalized before death. (Yaffe, 2002, p. 2096).

Yet, delay of nursing home placement can be done, and there is a good public policy reason for doing so: "One researcher estimated that a 1-month delay in the institutionalization of people with Alzheimer's disease could save as much as \$1.12 billion annually in the United States." (Yaffe, 2002, p. 2096). This delay is definitely possible; Yaffe notes that a "comprehensive support and counseling intervention for spouse-caregivers of patients with Alzheimer's disease reduced time to nursing home placement by nearly one year compared with those not receiving the intervention.... One of the key components of that intervention was to teach the caregivers behavioral management techniques to reduce difficult patient behaviors." (Yaffe, 2002, p. 2096). Another researcher noted, "estimates show 80-90% of behavior problems can be prevented by modifying the environment of the person with Alzheimer's disease, including caregiving approaches." (Reines et al, 2002, p. 2).

However, as Feinberg (2001) notes, "While delaying institutionalization is an important policy goal, it also means potentially increasing the emotional, physical and financial toll of family caregivers as they continue to provide care at home and in the community. Therefore, in any long-term care delivery system, programs and services must support and strengthen family and informal caregivers." (p. 3).

Summit participant Marti Sanville echoes that concern. "It's hard to balance keeping folks in their homes and helping them avoid being isolated. People need the options for what will work best for them – home support, a group residential setting, or some other arrangement."

And so our task is to not only try to figure out how to resolve situations of abuse and aggressive behavior so that at least some of these elders with Alzheimer's disease can remain at home, but to do so in a way that is respectful of the whole family.

Scope of the project

Defining terms is always problematic. Whole summits have been devoted to definitional issues alone. We definitely do not want to spend a lot of time figuring out the exact boundaries of what will and won't be considered "aggression" or "abuse." Exact definitions may be needed by lawmakers and law enforcers, but in the community -- in individuals' lived experience -- legal definitions are mostly irrelevant. Instead, people define their problems in broad terms that vary from person to person, situation to situation.

For the purposes of this project, then, we are broadly defining our scope as situations in

which there is a person with Alzheimer's disease who is being physically or emotionally hurt or at risk of being hurt, or who is physically or emotionally hurting or at risk of hurting someone else. We expect and accept that definitions of “hurt,” “at risk of being hurt,” and “at risk of hurting” will vary from individual to individual, situation to situation. What is important is that there is or is perceived to be a situation that has resulted or may result in harm to someone.

Under this working definition, intentionality is not a necessary component. Issues of power and control may be present or may not. There may be a pattern of problematic behavior, or it may be one incident. Although it is crucial that questions and Issues such as these be addressed in each situation as part of the assessment process, their presence or absence does not limit their inclusion in our scope.

We *are* excluding from the scope of this discussion the issue of financial exploitation. Although financial exploitation frequently co-occurs with other forms of abuse, existing systems such as adult protective services and law enforcement are appropriately charged with intervening.

We are also temporarily excluding situations solely involving safety issues such as whether a person with Alzheimer's disease who lives alone presents a fire risk if she or he still attempts cooking. These situations may end up being addressed by the Dementia Response Teams, but the protocol that we need to develop now is focused on aggressive or abusive behavior, not general safety risks.

Because there are significant issues of institutional culture, staff levels and training, and regulations involved in handling aggressive and/or abused persons with Alzheimer's disease residing in long-term care facilities, we are similarly limiting discussion of how to address abuse/aggression in institutions. Dementia Response Teams may well end up consulting in such situations, but the question of how to better handle abuse and aggression in institutional settings deserves far more specific attention and thought than we are going to be able to provide at this Summit.

Similarly, we are focusing only on people with Alzheimer's disease instead of including those with other types of dementia or cognitive problems. If we included the other dementias, we would need to address many additional medical and physical issues; resource limitations preclude that at this point.

Prevalence of abuse and aggressive behavior

How common is aggressive behavior? In their study of 147 caregivers of persons with dementia, Phillips and Egner (undated) found that 36% of the care receivers were reported as being verbally aggressive or abusive, and 27% were reported as being physically aggressive. The American Medical Association tells doctors, “agitation and

aggressive behavior have been reported in 65% of community-dwelling persons with dementia.” (1999, p. 27). A California Alzheimer’s group says, “the majority of AD patients experience some form of behavioral symptoms such as anxiety and agitation during the course of the disease.” (California, 2002, p. 7).

In pre-Summit materials we sent out two full articles on the linkages between abuse and dementia: Coyne (2002), *The Relationship Between Dementia and Elder Abuse*, and Wolf (1998), *Caregiver Stress, Alzheimer's disease, and Elder Abuse*. Therefore, the main points are summarized very briefly below.

- “Estimates of the prevalence of abuse of older adults suffering from dementia...far exceed the 1% to 4% prevalence rates typically cited for all elderly adults, cognitively intact as well as demented....” (Coyne, 2002, p.2).
- In general, how advanced the Alzheimer’s disease is has little, if any, effect on the rate of abuse. However, persons with Alzheimer’s disease who are aggressive tend to be abused more often.

The following chart, from Wolf (1995, p. 12), summarizes the findings of four early studies.

| Prevalence of Physical Abuse Among Dementia Caregiver-Care Recipient Dyads | | | | |
|---|---------------------|------------------------|-----------------------|-----------------------------|
| | Steinmetz (1988) | Paveza et al (1992) | Coyne et al (1983) | Pillemer & Suitor (1992) |
| Patient to caregiver | 18% | 16% | 33% | 25% |
| Caregiver to patient | 23% | 5% | 12% | 6% |
| Mutual: caregiver & patient | | 4% | 9% | |
| Either caregiver or patient | | 17% | | |

Cultural differences also play a part in abuse. Some behaviors – such as giving someone the “silent treatment” – are viewed as extremely abusive in some cultures. On the other hand, in some cultures screaming at others during conflicts is deemed quite normal. Being respectful of how cultural norms may interact with abuse and neglect definitions is important. However, keep in mind this point: The California Workgroup on Guidelines for Alzheimer’s Disease Management (2002) reminds us, “The most important aspect of cultural competency for providers to recognize is that there is more diversity within ethnic groups than between ethnic groups.” (p. 10).

Here’s an example of how cultural norms can interact with abusive behavior. Summit participant Pat Anderson told of one case she was involved with:

There was an older American Indian woman who had moderate dementia. She was abused by her hired caregiver. She became quite depressed because of the cultural conflict she was experiencing. In her culture, elders were to be respected. In being abused, she clearly experienced a lack of respect. There was a significant worsening of her cognitive condition. We were afraid to move towards prosecuting the abuser because we were concerned that the elder would have to testify and this would be further traumatizing to her. She was also growing increasingly vague, so she couldn't accurately defend her situation. She also regressed to using her native language and she was intimidated by the legal system. Usually we work with a victim compensation person. However, this person was so busy she didn't have time to work with this older woman. This was extremely distressing to the American Indian woman's family. They didn't want this caregiver to do this to anyone else. The monitoring of caregivers wasn't fail proof. We need to make sure that people aren't able to traumatize other people. We need some kind of registry so they cannot do this again.

The experience of Alzheimer's disease

At the Summit, we will receive a short orientation to Alzheimer's disease. However, there are some key points that bear repeating here because of their relevance to what we'll be working on.

Summit participant Cathy Kehoe notes that, "whenever I work with people who aren't familiar with dementia, they don't understand that people with dementia *can't* learn, that you have to rely on what they already knew. However, the person does have access to any trauma they had when they were young, so that's going to come up."

As an example of short-term memory loss, summit participant William Hanrahan notes that when he worked in a program for homeless veterans, "people with dementia would come in to the shelter banged up. They didn't want medical assistance. They had no recollection of an event that must have been traumatic; they'd say, 'I wasn't there.'"

Reminiscence expert John Kunz notes, "Reminiscence and life review approaches are essential in treating older adults with dementia. The older, implicit, emotionally charged memories last longer and are a strong asset. Older adults with dementia may also retreat to past memories due to boredom, isolation, and loneliness or to meet other unmet human needs." (p. 4)

The caregiving experience

Who caregivers are.

The American Medical Association calls them "the hidden patients." (1999, p. 26).

They are generally women (one study found 72% were female). Spouses make up about 36% of caregivers, 29% are daughters, 8% are sons, 20% are other females, and 7% are other male relatives. For primary caregivers, spouses make up almost half. (Montgomery, p. 1). These caregivers' needs vary based on whether they live with the care receiver, whether they are spouses or children of the care receiver, and when they define themselves as "caregivers."

Spouses tend to define themselves as caregivers far later than do adult children because spouses are expected to care for each other throughout the lifespan, whereas children typically perceive a definite change in roles when they begin handling tasks for their parents that their parents used to handle. Because of these differences as well as generational ones, "Children [who are caregivers] are more likely to seek information about the disease process, the availability of community services, and legal and financial information. Spouses need help with coping skills and information about behavior management and about in-home support services." (Montgomery, p. 11).

Cultural differences also play a role. "Because minority women have a greater probability of being single, the prevalence of daughters as the primary caregiver is considerably greater among Black and Hispanic populations than among Caucasian populations. The limited number of studies of these cultural groups suggests that adult children account for almost 75 percent of the caregivers versus the 40 to 60 percent that have been found in studies of white populations....Consequently, the daughters who care for minority elders tend to express a need for and use more in-home services and adult day care when it is available.... At the same time, minority families tend to include a larger number of persons in the caregiving constellation." (Montgomery, p. 10). Summit participant Pauline Boss notes that in both Native American and African-American cultures, caregiving is more shared among family members than is the case with European-Americans, about which she says, "one person in the family is assigned the care. Others may contribute money or visits, but tend not to do the grunt work. Isolated is exactly what it is. In the more extended-family models, it's easier."

Another factor that plays a role in the caregiving experience is whether the caregiver lives with the care receiver. Feinberg (2001) says, "Family caregivers of persons with cognitive impairments are more likely than those who care for persons with physical impairments to be involved in everyday care and supervision of their loved one." (p. 5).

The overall experience.

has been well characterized by Summit participant Carly Hellen in her 1998 book, Alzheimer's Disease: Activity-Focused Care, (2nd edition). She is quoted here at length.

"The family's journey through the decline of their loved one's cognitive and physical abilities is often a long and involved struggle. Emotions, responses, hopes, joys, and sadness become like a roller coaster ride for all persons involved with the resident with

dementia. The ambiguity of good moments or days in contrast with difficult periods becomes a challenge. Even the times of being or not being recognized by the resident wrench the hearts of caregivers because they never know what response will be forthcoming. The resident often looks well physically, which causes outsiders to question the caregiver's talk about incompetence or medical system failures.

"Family members often experience isolation from friends, frustration, anger, exhaustion, and loss of patience. They strive to understand what is happening to their loved one, and they struggle together against the progressive dementia.

"Family members may experience difficulty accepting the diagnosis of Alzheimer's disease or related disorders. They maintain an inner hope that the resident does not have dementia as physicians cannot be absolutely positive until the brain tissue is studied. Families may sometimes look for signs that the resident is getting better or hope that a cure will be found in time.

"During the resident's middle to late stages of dementia, the family usually does their best to give care and cope with their own grief. They are forced into problem solving from the simplest dressing task to complex issues such as toileting, safety, and mobility. New roles and approaches need to be learned. Men may have to learn how to prepare meals and do tasks their wives at one time handled independently. Women may need to learn about family finances or, in some situations, learn how to drive. Caregivers are put into the position of making decisions regarding appropriate care, and often place themselves at risk emotionally and physically." (p. 379).

"Typical experiences of loss, grief, and change for the family members may include:

- I. *Changes in the family member's relationship with the resident:* personality changes; difficulties with communication and understanding each other; role reversals and changes in previous relationship; need to take on decision making; weathering the resident's behavioral challenges and emotional changes; and possible embarrassment or need to make excuses for the resident
- II. *Changes in the family member's previously held dreams of the future with the resident:* experiencing changes in the person the resident used to be; challenges to rebuild the plans of today as well as for the future; changes in financial support for the future; disappointment of putting aside personal plans to be able to tend to the present situation of caregiving for a loved one with a progressive brain disease; grieving lost opportunities to share family joys
- III. *Changes in the family member's daily life living:* days lived that focus around the resident and caregiving; becoming isolated from friends and social support; possibility of becoming over-involved in resident care; feelings of

limited time for personal interests; role ambiguity

- IV. *Changes in the family member's personal well-being:* possibility of depression; risks of overwhelming fatigue; feelings of being overwhelmed or alone on the journey of dementia caregiving; manifestations of physical health problems; need to be listened to and validation of his or her personal caregiving story; need to have options that offer a safe arena to process feelings, grief, and needs." (p. 380).

Caregiver stress.

There is no doubt that caring for someone with Alzheimer's disease is stressful physically, emotionally, and in many other ways. Summit participant Pauline Boss, in her 2002 book Family Stress Management: A Conceptual Approach (2nd edition), quotes a study of elderly spousal caregivers living at home with their care receiver and "who provide support to their spouse and report caregiving strain are 63% more likely to die within 4 years than noncaregivers." (p. 10).

Caregiver stress is partially a function of how caregivers approach life. Boss (2002) defines the "protective factors" against stress as "(a) attribution style (externalizing the blame to explainable forces rather than internalizing it to unexplainable forces or oneself), (b) response style (distracting oneself vs. ruminating), (c) cognitive style (being an optimist vs. a pessimist), (d) social skills (connecting vs. isolating), and (e) problem-solving skills (seeking help from others vs. stoicism and going it alone." She notes, "it is important to know that protective factors can be learned." (p. 76).

In a related finding, Archbold, et. al. (1995) found that caregivers who have a positive relationship with the care receiver experience less strain because they find caregiving inherently meaningful. They measured this "mutuality" by a 15-point Mutuality Scale that included questions such as "How close do you feel to [your care receiver]?" and "How much do you confide in [your care receiver]?"

Another factor relating to stress is whether a family is fatalistic, believing nothing can be done to change a situation. Boss (2002) found fatalism is often associated with having few resources, although she said it remained to be seen which came first: fatalistic beliefs or a lack of resources. (p. 142). A fatalist belief set can help a family adapt to things they cannot change, but can also lead families to ignore what can be improved. (pp. 138-143). On the other hand, cultures (including the predominate culture in the U.S.) that emphasize mastery over difficulties are prone to blaming the victim. "If a person believes in a just world and values mastery, he or she may also believe it is not logical for bad things to happen to good people and will therefore blame the victim." (p. 146). Such families, faced with a progressive disease like Alzheimer's, may experience a great deal of stress from the mismatch between their belief that anything can be mastered with enough effort and their experience of caring for someone with

Alzheimer's, who does not get better. (p. 150).

Clearly, how caregiving is arranged and given, how behaviors are perceived, and how outsiders respond to a situation are all affected by cultural mores and differences. Boss (2002) adds that cultural difference can magnify caregiving stress: "prejudice, intolerance, and bigotry are external stressors that are cumulative with other stressors." (p. 25).

Depression

Depression among caregivers is common. Caregivers, particularly those caring for a spouse with Alzheimer's disease, show higher rates of depression than noncaregivers. One study found that non-caregiving spouses had depression rates of 15%, compared to a rate of over 40% for those caring for spouses with Alzheimer's disease. This depression rate did not ease after the person with Alzheimer's disease died: 41% of one sample of former spouse caregivers "showed mild to severe depression at two to three years after their spouses' death – not significantly less than the 43 percent depression rate among current caregivers." (Grabmeier, 2001).

Boss found in her work that caregiver depression is related to caregiver perception of the care receiver. "I studied the families of seventy patients with Alzheimer's, almost all of whom were from the Upper Midwest. The severity of the patients' dementia bore no relationship to the extent of their caregivers' depressive symptoms. Rather, it was the degree to which family caregivers saw the patients as 'absent' or 'present' that strongly predicted their depressive symptoms, and this connection was even stronger three years after my initial visits with the families." (p. 15). "With Alzheimer's, the more uncertain a family member is about the patient's status as absent or present, the greater the family member's symptoms of depression." (p. 45).

Ambiguous loss

One way of looking at caregiver stress and depression is through what researcher and therapist Pauline Boss has identified as "ambiguous loss." "Perceiving loved ones as present when they are physically gone, or perceiving them as gone when they are physically present, can make people feel helpless and thus more prone to depression, anxiety, and relationship conflicts. How does ambiguous loss do this? First, because the loss is confusing, people are baffled and immobilized. They don't know how to make sense of the situation. They can't problem-solve because they do not yet know whether the problem (the loss) is final or temporary. If the uncertainty continues, families often respond with absolutes, either acting as if the person is completely gone, or denying that anything has changed. Neither is satisfactory. Second, the uncertainty prevents people from adjusting to the ambiguity of their loss by reorganizing the roles and rules of their relationship with the loved one, so that the couple or family relationship freezes in place. If they have not already closed out the person who is missing physically or psychologically, they hang on to the hope that things will return to

the way they used to be. Third, people are denied the symbolic rituals that ordinarily support a clear loss – such as a funeral after a death in the family. Few if any supportive rituals exist for people experiencing ambiguous loss. Their experience remains unverified by the community around them, so that there is little validation of what they are experiencing and feeling. Fourth, the absurdity of the ambiguous loss reminds people that life is not always rational and just; consequently, those who witness it tend to withdraw rather than give neighborly support, as they would do in the case of a death in the family. Finally, because ambiguous loss is a loss that goes on and on, those who experience it tell me they become physically and emotionally exhausted from the relentless uncertainty.” (Boss, 1999, pp. 7-8).

Boss notes that prolonged ambiguous loss such as that represented by Alzheimer’s disease can lead to conflict: “Few people, professionals or family members, can tolerate for long being in a situation that is out of their control. The stress is too much. As the ambiguity persists, conflicts increase, not just among family members, but also between the family and clinicians.” (1999, p. 51).

It can also lead to immobilization: “The tension that results from conflicting emotions [such as dreading the death of a person with Alzheimer’s but also hoping for closure], especially when family members’ unresolved grief is not acknowledged, becomes so overwhelming that they are frozen in their tracks. They cannot make decisions, cannot act, and cannot let go.” (Boss, 1999, p. 61). “In this painful process, one of the complications is denial. Sometimes loved ones faced with the threat of loss refuse to see what others see, to hear what others hear, and to acknowledge a painful reality.” (Boss, 1999, p. 80).

Caregiver coping with problematic behaviors

As noted previously, the majority of persons with Alzheimer’s disease show some type of aggressive, agitated, or problematic behavior during the course of the disease. How the caregiver deals with this behavior has a great deal to do with his or her experience of caregiving. In Summit participant Theresa Harvath’s 1994 article (sent out in the second pre-Summit packet), she notes, “Studies comparing the effects of the care receiver’s behavior problems with other symptoms caused by dementia (e.g., social or cognitive dysfunction) show that the behavior problems are consistently more predictive of negative consequences for the caregiver than the other symptoms.” (p. 8).

Summit participant Pauline Boss says the caregiver’s perception of what is going on is the “kingpin, the most powerful predictor” of stress. “You can have a patient with deep dementia and can be doing just fine. On the other hand, marital fights can break out if the well spouse thinks the one with dementia is still who they were, if the caregiver says, ‘they’re doing it on purpose.’ The window for intervention is through the caregiver’s perception.”

Summit participant Devon Christianson cautions, “when we look at caregiver stress, we primarily think it’s an *uniformed* caregiver. I would challenge that. It’s not necessarily the case. Yes, they don’t understand the disease, but it’s been an intense marriage, it’s a marriage pattern. They will believe, no matter how much you tell them, that the person with dementia is doing this on purpose. The wife says she knows her husband, not us, and he has *always* known how to push her buttons.”

Each caregiver finds different behavior difficult. However, in a test of the Problem Behavior Inventory (BPI) (which we will discuss in the section on assessment tools), its developers assessed 147 caregivers. Out of 25 problem behaviors, the ones that caregivers were most bothered by were (on a scale of 0 = not at all to 4 = completely):

- Being sexually inappropriate (score of 3.23)
- Wandering off (3.00)
- Misbehaving in public so that you can’t go out with him or her (2.28)

All other scores were below 2.0. (Phillips, undated).

Harvath (1994) studied ten female caregivers of persons with dementia and found that “the consequences for family caregivers resulting from the care receiver’s aberrant behaviors [e.g., aggressive behavior, losing things, lapses in hygiene, problems managing money] are mediated by two sets of variables...the caregiver’s interpretation of the behavior and the caregiver’s management of the behavior.” (p. 13).

“The caregiver’s interpretation of the care receiver’s behavior involved three dimensions: her attribution of the cause of the behavior, her perception of the care receiver’s volition or control over the behavior, and her assessment of the problematic nature of the behavior.” (p. 13).

“In general, caregivers who perceived that the care receiver could not control his/her behavior found managing the behavior less stressful than caregivers who believed the behavior was intentional.” (p. 15).

“Caregivers who perceived that the care receiver’s behavior was a result of situational circumstances often tried to avoid those situations or to monitor the care receiver more closely.... In contrast, caregivers who perceived that the situation was a threat to their well-being or that the care receiver could control it often intervened in direct, confrontational ways.” (p. 17)

Summit participant Mary Bouche put it very simply, “Some people still believe people are responsible for their actions, no matter how advanced the dementia.” Summit participant Sally Carpenter concurs: “There is so much available in the media regarding handling challenging Alzheimer’s disease behaviors, but families are inclined to believe that the person with Alzheimer’s disease is behaving intentionally.” Summit participant Theresa Harvath discussed a case in which “the mother had a previous needy and dependent personality, so the daughter caregiver had trouble determining what was

dementia and what was the old pattern.” For instance, the daughter pointed out that the mother “can walk when we come into the clinic, but as soon as we leave here, she takes these little steps.” Summit participant Kathleen Quinn also has these concerns. She says she talks to adult protective services workers who report that families say, “Dad knows these other things, so how can he not be intentional about hitting me?” Just what Dad “knows” may be questionable, however. Quinn reported one case where “the family said Dad could get out of his chair without help, and they demonstrated that by throwing a pan of water in his face. Under that circumstance, he could, in fact, get up.”

Summit participant Devon Christianson gave two examples from her caseload where she perceived the caregiver view was actually causing the “problem.”

In the spouse case, the husband has dementia. He’s driving her crazy, she doesn’t like who she has become, and she’s full of anxiety. We march over with all of our packet of good tools: caregiver classes, day care, workers...on and on. This couple has the resources to pay for it. What is driving me crazy is the woman’s perspective. This woman is a perfectionist: her life was full of little boxes, and there’s not a speck of dust in the house. The man is very passive, pleasant, and communicative even though he has AD. He can walk around the block and find his way home. He’s never aggressive, and mostly sleeps. She can leave him alone safely. But...he asks her repeated questions throughout the day to which there are no good answers. Information does not help this situation. She doesn’t want help in changing her perspective and life pattern of coping. She will continue to have this be a bad situation. She says, “You have to understand, the only thing that’s going to help me is for him to change.” She calls day in and day out and goes out of her head. Information’s not helpful, therapy is not helpful. There’s no way to convince her otherwise. We can’t get her to see it’s her doing this.

In the other case, the daughter calls in tears, can’t take it anymore. She has no support from her siblings. Dad drives, cooks, cleans, has only light memory loss, and totally functions independently in his own home. Daughter’s stress is her perspective is that he needs her. Her perspective is she is so overwhelmed. He’s not even day care appropriate. He has a girlfriend.

Harvath (1994) looked at the impact of a caregiver’s measure of success, which, she says, “Seemed to influence her assessment of whether a certain behavior was a problem, and also, her choice of intervention strategies. It also played an important role in determining the consequences that resulted from managing problem behaviors. Caregivers whose measure of success exceeded what seemed possible for the care receiver, given the care receiver’s level of cognitive impairment, were frequently disappointed or frustrated when the outcome fell short of the goal. In contrast, caregivers whose measure of success seemed more consistent with the care receiver’s cognitive and functional capacity – who defined success in more modest terms –

seemed more satisfied with the outcome of managing problem behaviors, even if it did not involve complete resolution.” (p. 20).

Harvath (1994) concludes, “More specifically, caregivers who interpreted that the care receiver could not control the behavior, used less confrontational styles of intervention, and set realistic goals seemed to experience fewer negative consequences than caregivers who believed the care receiver acted deliberately, used confrontational styles of behavior management, and had high expectations with respect to the care receiver’s behavior.” (pp. 20-21).

It’s important to note that there can be a relationship between caregiver perception and possible abuse. Kilburn (1996) studied the violent *feelings* that caregivers had toward care receivers with Alzheimer’s disease. He found, “Disruptive behavior by the care-recipient was related to higher probabilities of caregivers’ believing that they would become violent.” (p. 78). He also found that, “living with each other was a strong predictor of caregiver to care-recipient violent feelings, as was low self-esteem.” (p. 78).

Emotional abuse and neglect can result from caregivers’ inability to cope with their loved ones’ cognitive issues. Summit participant Mary Salzeider notes, “some of the worst hurts appear subtle on the surface.” She cites her own family, in which her mother had always been “ditzy,” and it took some time for the family to recognize the Alzheimer’s disease. Before that recognition, “there was tension between [Mom and Dad] because Dad didn’t understand the disease. For the first couple of years, he put her down. He hurt her self-esteem and blamed her.... It got a little better as Dad understood this was more than Mom, that there was something unusually wrong.” She also says that in her experience, “with family members, abuse is more emotional. There can be neglect because the person is very, very hard to deal with or communicate with, so they’ll write them off.”

Caregiver assessment of care receiver

Unfortunately, says Summit participant Theresa Harvath, “Caregivers are very poor appraisers of cognitive impairment. There are studies that compare actual [Mini Mental Status Exam] scores with caregiver predictions, and they’re often way off.” Grigsby and colleagues (1998) found that people who performed well on the MMSE but performed poorly on their Behavioral Dyscontrol Scale (BDS) “tend to be viewed by their spouses and caregivers as deliberately engaging in obnoxious behavior. (For descriptions of both the MMSE and the BDS, see the section in this paper on assessment tools.) In fact, our findings suggest that such people are unable, not unwilling, to control their behavior.” (p. 19). This appears to be common: “In one clinical sample, we found that over 20% of a clinical sample of VA patients had a poor BDS score in association with a normal MMSE score.... Among 1145 community-dwelling older adults, about 10% fell into this category.” (p. 20).

Mr. T was a 78 year-old, divorced, retired barber with an 11th grade education,

admitted to the VA Nursing Home Care Unit for rehabilitation and physical therapy after a long hospital stay. Nursing staff reported that he had significant behavior problems, describing him as manipulative, irritable, impulsive, and very inconsiderate of others. Although he was able to take care of himself, he seldom did so without repeated reminders. On one occasion, he urinated in his denture container, and he generally was disruptive in the nursing home environment. He was articulate, could describe the procedures necessary for care of his venous ulcer and personal hygiene, and obtained a normal score on the MMSE (27 out of a possible 30 points). Because of this, the nurses were convinced that he was being willfully and deliberately obnoxious. On the BDS, however, Mr. T. obtained a score of only 4 out of 19 possible points. This score indicated severe impairment in his ability to engage in very simple motor behavior. He was completely unaware of his mistakes, and considered himself to have done reasonably well on the evaluation. The fact that Mr. T. had been unable to perform simple motor tasks suggested that he would have difficulty with more complex behavior, and indeed this seemed to be the case. A CT scan of his brain demonstrated significant atrophy of the prefrontal cortex, an area that is of great importance for the executive functions and the regulation of behavior. (Grigsby, 1998, p. 20).

Executive function

Part of the reason why caregivers have such difficulty in accurately assessing what is going on with a person with Alzheimer's disease is their confusion between memory, cognition, and executive function. Grigsby and colleagues (1998) have studied executive dysfunction, or an inability of the brain to use intention to guide behavior. "The executive abilities involve relatively complex behavior, including planning, active problem solving, working memory, anticipation of possible consequences of an intended course of action, initiation of activity, inhibition of irrelevant and inappropriate behavior, and the capacity to monitor the effectiveness of one's own behavior." (p. 590).

"Behavioral disorders characterized by impulsivity, distractibility, inappropriate behavior, perseveration, apathy, and failure to initiate purposeful behavior, reflect a dissociation between volition and action. That is, individuals with a dysexecutive syndrome demonstrate varying degrees of inability to use an intention to guide their behavior...." (Grigsby, et al., 2000, p. 4). "As a consequence of a dysexecutive syndrome, some individuals may be deficient in the ability to initiate the behavior required to satisfy the intention, whereas others may be unable to inhibit behavior irrelevant (or inimical) to its satisfactory resolution." (Grigsby, et. al., 1998, p. 591).

It is important to recognize that an individual's cognition may be very different from their executive ability. "If the intellect is relatively intact, but the ability to regulate one's activity is deficient, competency may be compromised in a way that the standard mental status examination cannot detect. Patients may be able to think abstractly, yet be unable to initiate or follow through with appropriate behavior. Other patients may be

essentially amnesic yet retain the capacity to regulate their activity.” (Grigsby, et al., 1995, p. 174).

Grigsby (1995) also notes, “Individuals with an impaired capacity for behavioral self-regulation are likely to be viewed by others as unmotivated, uncooperative, stubborn and manipulative, especially when other cognitive abilities are within normal limits.” (p. 175).

In a study of more than 1,000 community-dwelling elders, Grigsby and colleagues found that about 10.1% of study participants who were impaired on the Behavioral Dyscontrol Scale (BDS) had normal scores on the MMSE. Similarly, 9.8% of those who had a normal BDS score were impaired on the MMSE. (Grigsby, et al., 1998, pp. 593, 595).

Family dynamics

Families that include a person with Alzheimer’s disease bring a complex history with them. Summit participant Sally Carpenter cautions that “dysfunctional families have been dysfunctional for 50 years.” Summit participant Mary Salzeider mentioned one implication of this fact: “behaviors are habit-forming.” When her father began to understand her mother’s dementia, “there was some change [in his put-down of his wife], and there was not some.”

Past trauma

Past trauma can affect a whole family for decades. Boss (2002) notes, “Families that appear to be coping [with a traumatic event] may not really have resolved the issue and, years later, may manifest the crisis when a similar event triggers past memories.... The chain reaction phenomenon appears only when a current loss or separation reactivates an earlier family loss that was never fully grieved or resolved.” (p. 87).

In addition, the effects of trauma can be passed through the generations: “As a family stress researcher and therapist, I have seen such families. A victimizing event may have happened to one or both parents when they were children; they teach their children to numb their emotions, to stay disconnected from other people, and to distrust others. Unless these family rules are changed, when these children grow up and become parents, they will also pass the disorder on to the next generation. In this way, [post traumatic stress disorder] can be found in families and individuals.” (Boss, 2002, p. 163).

Displaced aggression

Displaced aggression may also take place, where stress between two members of a family ends up getting played out in another dyad. Summit participant Pauline Boss says that she has noticed that in cases where an adult child is the caregiver, that

caregiver's marriage may suffer. "There's a high cost for adult child caregivers – usually a cost on her/his marriage. That configuration just won't work any more, with overburdened women and overburdened men. It sometimes causes aggressive behavior. The aggression may not be directed to the elder but to the partner or kids. I have seen aggression toward spouses on the part of wives who are preoccupied with parental caregiving. The marital problem is the elder problem."

Unclear boundaries.

Sometimes families have unclear boundaries. Summit participant Tiffany Lodholz notes, "caregivers often don't think they are doing anything wrong, when they sometimes are, such as providing massages and things go too far."

Domestic violence

We were unable to locate *any* articles specifically addressing long-term domestic violence in couples or families where one or more of the family members develop Alzheimer's disease. This does *not* mean that spousal/partner abuse suddenly stops when either the perpetrator or victim becomes demented. In fact, given that domestic violence is usually understood as a pattern of one person seeking to exert continuing "power and control" over their spouse or partner, it seems likely that the onset of dementia – with its consequent negative impact on the ability of both the person with Alzheimer's disease and his or her caregiver to control what is happening to them – might actually *worsen* long-standing patterns of domestic violence, as the abuser seeks to regain control and power over the situation and their partner.

Exactly how prevalent domestic violence is among older couples is a matter of some debate. In their review of more than 50 research studies of domestic violence in later life, Brandl and Cook-Daniels (in press) found only two that estimated how much domestic violence there is among older couples. In a 1996 review of 842 couples aged 60 and older from the 1985 U.S. National Family Violence Resurvey, Harris found that 5.8% of older couples had experienced physical violence in their relationship within the past year. More than half of these elders said their spousal abuse began more than 10 years before, and 40% said the first incidence of violence occurred 25 or more years before. In a study of 257 women aged 50 to 79 participating in a health program in New Jersey, Mouton (1999) found that 4.3% were currently in an abusive relationship.

It is important to note that in long-standing domestic violence, it is frequently unnecessary for the abuser to physically assault his or her victim. Instead, verbal or even nonverbal threats may be all that is necessary. The domestic violence in later life "Power and Control Wheel" that was enclosed in the first pre-Summit packet enumerates 31 "tools" *other* than direct violence that abusers use to exert power and control over their victims.

“Benign” causes of aggressive/agitated behavior by person with Alzheimer’s disease

A frequent issue that has come up around this project is how often the disease itself causes aggression. Many people seem to take the stance that there is nearly always a reason for the aggressive behavior. Hellen (1998), for instance, says, “Almost every behavior is a demonstration of a purpose or reflection of a reason.” (p. 198). Although the “possible factors precipitating unwanted behaviors is endless,” she gives the following list: “undiagnosed fractures, chronic pain, fatigue, current pain, possible urinary or bowel retention, anemia, hypoglycemia, dehydration (may lead to late-day agitation), nightmares and an inability to move from the dream sleep state into the awake reality, seizures, prostate problems, prolapsed bladder or uterus, depression, disconnection (due to not having abilities fully engaged), feelings of abuse or being invaded during ADLs [Activities of Daily Living], and a negative response to caregiver’s size, age, gender, race, foreign accent or foreign language being spoken.” (p. 198).

Environmental strains

Summit participant Jeff Lewis notes that the environment can cause persons with Alzheimer’s to seem “aggressive.” “Sometimes there are very simple issues that need to be addressed, like someone not being paired appropriately with a roommate, or someone’s gait being wide and needing more space to move: in other words, their cane movement may have been striking people because they didn’t have enough room, or they were frustrated because they didn’t have enough emotional space to easily or comfortably move.”

Sensory overload

Sensory overload can also be a problem:

Sam appears angry most of the time. He demonstrates his frustration by ripping up activity supplies, writing curse words on scraps of paper, and being combative during bathing and dressing activities. He has a hearing deficit and was admitted to the facility wearing two hearing aids. Several months after admission, Sam probably threw out or misplaced one of his hearing aids. His wife was informed and she began the process of ordering a replacement. During the period that Sam wore just one aid, his agitated behavior decreased. He no longer was difficult to bathe and dress. He stopped destroying objects and ceased other displays of anger. It became apparent that the presence of two hearing aids provided too much ‘noise’ for Sam and was the source of his frustrated behavior. (Hellen, 1998, pp. 89-90).

Interpersonal strains

Summit participant Pauline Boss says in her research with colleagues, “we found a circular, feedback connection: if the caregiver is troubled by ambiguity, they are depressed, and the more depressed they are, the more the patient acts out, and it circulates. So the implication is to keep the caregiver from being depressed and you’ll have a calmer patient.”

Persons with Alzheimer’s disease can misinterpret what’s going on around them. “Activities of Daily Living could be misinterpreted by the resident as aggressive or abusive care,” Hellen (1998), says. “Acting out, combative, and difficult behaviors often occur during the resident’s morning period of bathing and dressing. For example, if the resident has limited ability to understand the nature or reason for the task, rubbing the resident’s hair dry, combing snarled hair, brushing teeth, clasp a tight bra or pant waist, pulling up elastic hosiery, or pulling a sweater down over the head and eyes of the resident may be interpreted by the resident as physically abusive. This response is heightened when the resident is hypersensitive to touch or dislikes to have his or her personal space invaded.” (p. 90).

Similarly, “Being dressed and, therefore, clothing, is very much a symbol of having it ‘all together.’ When the ADL task involves undressing the resident, he or she often experiences combativeness or increased anxiety.” (Hellen, 1998, p. 93).

Fear and escalation

Hellen (1998) says flatly, “Realize that fear is usually the number one emotion felt by persons with dementia.” (p. 199). She notes that fear often escalates: “A physically aggressive or combative resident is a frightened resident.... Intervention should happen long before the resident feels the need to *respond* by hitting out, pushing, shoving, kicking, hair pulling, scratching, or biting. Usually, the resident has displayed signs of the impending escalation of emotions.” These signs include:

- Changes in physical activity, such as pacing, other movements, or becoming quiet or withdrawn; clapping hands; upper-body shaking or tremor
- Body language (e.g., threatening gestures, reddened face, fists, rapid eye movement, refusal to respond to redirection, no eye contact with person attempting to offer redirection)
- Verbal cues (e.g., raised voice, rapid speech, muttering, humming, whistling, obscene or threatening language, stuttering, calling out). (pp. 211-212).

Medical conditions

Persons with Alzheimer’s disease may be aggressive because that is the way they are expressing other medical problems. Flaherty (1994) quotes a study about the frequency of co-existing medical conditions: “As for general physical health, people with dementia have been shown on average to have more than three co-existing medical conditions, including hearing impairment (50%), cardiac illness (40%), arthritis (37%)

and hypertension (34%)....” (p. 83).

In an interview featured in the Wisconsin Bureau of Aging and Long Term Care Resources’ March 2002 Dementia Care Newsletter, Dr. Cary Kohlenberg states, “the three biggest causes of behavioral issues in people with dementia are untreated or undertreated pain, urinary tract infections and constipation.” (p. 4).

The California Workgroup on Guidelines for Alzheimer’s Disease Management (2002) clearly states that other medical problems should be ruled out. However, it cautions, “Since judgment and memory impairment are key features of AD, the Primary Care Physician should expect under-reporting of symptoms and problems.”

It is important to note that “many commonly used medications can be responsible for cognitive [and behavioral] changes”; a list of some are included on page 6 of the AMA dementia guidelines. [Author’s note: Copies of the AMA Dementia Guidelines will be available at the Summit.]

Depression and other mental illnesses

The California Workgroup on Guidelines for Alzheimer’s Disease Management (2002) noted that “moderate evidence...found an association between depression [in individuals with Alzheimer’s disease] and physical aggression.” (p. 8)

This workgroup also notes, “delusions, paranoia and hallucinations are the most common form of psychotic symptoms and are of great concern since these symptoms are often linked to aggressive, combative behaviors.” (California, 2002, p. 7).

Flaherty (1994) discusses a study of “217 mildly to moderately impaired Alzheimer patients, all of whom were living in the community, [which] indicates that 40.6 percent experience depression; 35.5 percent paranoia; 30.9 percent anxiety and fearfulness; 30 percent delusions; 24.9 percent demonstrate aggressive acts; and that 18.4 percent experience hallucinations.” (p. 83).

Summit participant Pat Anderson notes that 25% of those with a major mental illness have experienced a major trauma.

Post traumatic stress disorder (PTSD) and past traumas

Most, if not all, persons with Alzheimer’s end up reminiscing about past memories. Kunz (undated) says that reminiscence experiences may unintentionally bring up traumatic memories or events. The more cognitively impaired an individual is, he says, the more likely this is to happen. In addition, “individuals with dementing illnesses often lose their ability to explain their negative reactions or avoid these situations. As a result past issues are triggered without an understanding of what is occurring.” (p. 12).

Betty's memories are now easily triggered. One day, another member of the household began crying. Betty immediately began to cry as well, but not in relation to the other individual but to her past. She began to mutter, "He was a terrible man, that man was so mean, and he was such a mean man...." She was referring to abuse from her past and as she discussed this looked terrified. Staff talked with her at length and helped her remember how she escaped the abusive situation and what her life was like after that. Eventually, Betty was taken back to the safety and beauty of her world after the period of abuse. Betty is able to participate in reminiscence group and related activities. However, additional structure and caution need to be utilized in order to prevent the unintentional triggering of negative past memories, since she is losing the cognitive ability to do this on her own. (Kunz, undated, p. 21).

Studies estimate that approximately 25% of women and 15% of men have experienced childhood sexual abuse. (Allers, et al, 1992, p. 14). Studies have found that such victims frequently experience abuse as adults, as well. (Allers, et al, 1992, p. 16). Summit participant Pat Anderson cautions, "it's hard to get accurate information of earlier life assaults or abuses or aggression from people with dementia. It's difficult to get an objective life history, either because their partner may not have always been part of that dynamic or the partner isn't objective, either, or there are no other family members around." She also says, "it's very difficult for older women to talk about sexual abuse, likely because it's still so stigmatized. They are afraid of being further victimized about either early life or later life sexual assault. If they develop dementia, this is an extreme area of vulnerability. As they try to retain their resources, they fear exposing their earlier traumas." Summit participant Janice Griffin notes, "many people in their 70s and 80s have lots of incest issues they were never allowed to talk about." She speculates, "when people do become aggressive or mean, how much of that might be due to being 'pissed off' because of the incest or sexual assault that happened to them? Does it come to a point in their lives where people just give up those restraints and just start letting go of what used to hold them back?"

Hellen (1998) discussed one case of a "combative" resident. It turns out he "had been a prisoner in the extermination camps. When touched from the back or out of his visual field, he reacted swiftly with clenched fists, turning quickly and hitting the person who touched him. Being touched from the front was almost as threatening to Simon until he was able to trust a few staffpersons." (p. 77).

Traumatic memories may also return for other reasons. Miller (2001) defines PTSD as "what happens when the mind bites off more than it can chew. When someone is overwhelmed by an experience he's not prepared to cope with, his mind either blocks it out or chews it over and over to break it in to mentally bite-sized chunks. A key, defining symptom of PTSD is this alternation between avoidance and intrusion. Another is 'numbing,' or pulling the plug on outside stimulation, which is evidenced by flat affect and a loss of spontaneity." (p. 2).

Miller continues, “With the elderly, a recent traumatic event often reawakens memories of things that happened decades earlier. I refer to it as ‘mental shrapnel,’ which just sits there until they have a new injury. I had a patient, a man in his late seventies, who walked into a glass door. He was cut up a bit, but for some reason, it completely knocked him out. It turned out that he’d operated a liquor store in a rough neighborhood in Chicago for most of his adult life. He’d been held up, tied up and beaten numerous times. The way he described it was, ‘During the time I was working, I couldn’t afford to think about it because I had to make a living. When I retired and came to Florida, life was good, and so I still didn’t think about it. And then, this thing happened and it suddenly reminded me of all the other times that I came close to death.’ This is a very common theme – this ‘straw that breaks the camel’s back’ phenomenon.” (p. 2).

“Most of us who are fifty or younger grew up in the ‘post psychological age,’” Miller says. “We’re used to psychological-mindedness, sharing our feelings and talk shows where people bare their souls. But people who are sixty or seventy come from a generation that puts great value on stoicism, stability and sticking it out. The original, or ‘index,’ event may go back to a time when people just didn’t talk about those things, or if they did, they may not have been believed. Dwelling on the event may have been considered a sign of weakness, and they were told to ‘snap out of it!’ “ (pp. 2-3).

Abusive caregivers

Typology of abusers

In an article sent out in the first pre-Summit packet but worth recapping here, elder abuse practitioner and researcher Holly Ramsey-Klawnsnik (2000) laid out a typology of elder abuse offenders designed to help interveners decide whether someone who perpetrates elder abuse can be assisted. Briefly, her five types are:

- Overwhelmed offenders. These are the “caregiver stress” abusers. Ramsey-Klawnsnik defines them as “well-intentioned; they enter into a caregiving position expecting to provide adequate care. For the most part, they are qualified or fit care providers in personality, intelligence, caregiving skills, and motivation. However, when the amount of care expected from these individuals exceeds that which they can comfortably provide, they lash out verbally or physically. Alternatively – or additionally – the quality of their care may degrade to the point of neglect.... The maltreatment displayed by overwhelmed offenders is usually episodic rather than chronic in nature and worsens as stress and demands increase. When confronted regarding their actions, overwhelmed offenders may deny the allegations because they feel embarrassed or fear the consequences. Alternatively, they may defend their behavior as inevitable given the circumstances.” (p. 18).
- Impaired offenders. These are “well-intentioned care providers who have

problems that render them unqualified to provide adequate care to dependent people...[they] typically fail to recognize the inappropriateness of their actions and do not hide the maltreatment.” They may be “unqualified” due to having a developmental disability or mental illness or (if a paid caregiver) having been inadequately trained. (p. 18).

Domestic violence abusers (as well as other types of abusers) may be any of the following:

- Narcissistic offenders. These caregivers are motivated by anticipated personal gain, not a desire to help others. “They are excessively concerned with meeting their own needs, and do this by using other people and their assets.... [They] are not fit by personality or temperament to be care providers. They treat elders like objects, or means to an end.” (p. 19).
- Domineering, or bullying, offenders. “Domineering, or bullying, offenders feel justified in blaming and attacking others, particularly those over whom they perceive themselves as having power and authority. These offenders are given to outbursts of rage, and misuse relationships and positions of trust to justify exerting coercive control over others. They tend to externalize rather than internalize responsibility for problems. These offenders believe that their actions are justified, rationalizing that the victim ‘asked for it’ or deserved it, often because their own excessive, rigid expectations were not met.” (pp. 19-20).
- Sadistic offenders. These people “derive feelings of power and importance by humiliating, terrifying, and harming others. They take pleasure in their victims’ fear, and victims’ pleas to avoid abuse bring the offenders feelings of excitement and control. Sadists typically exhibit sociopathic personalities, lacking guilt, shame, or remorse for their behavior.” (p. 20).

Ramsey-Klawnsnik notes, “Overwhelmed and impaired offenders do not look for victims. Difficult circumstances lead them to neglect and abuse. Narcissistic, domineering, and sadistic offenders organize their lives to bring them into positions of power and authority over vulnerable potential victims.... Overwhelmed and impaired offenders are unlikely to threaten or harm their victims to prohibit cooperation with law enforcement or social services professionals. Services to reduce the caregiving burden and improve the quality of eldercare often prevent continuing maltreatment. Criminal prosecution is rarely appropriate or helpful in these cases. [In contrast], narcissistic, domineering, and sadistic offenders do not want to lose access to their victims or to face responsibility for their criminal conduct. They commonly intimidate their victims to prevent the latter from disclosing the abuse and seeking help.... Criminal prosecution is often appropriate....” (pp. 21-22).

Retaliation

Summit participant Kathleen Quinn says, “I’ve been saying for years that there’s been no research on the anecdotal situation where the woman has been abused and is now retaliating against the demented husband.” Despite this lack of study of this phenomena, there are anecdotes about such cases. Baxter (1996) reports on one that came to the attention of adult protective services:

Clyde was 78 years old, diagnosed with Alzheimer’s disease, living with his wife, Jean. At the initial assessment, Jean met the case manager at the door and talked non-stop for two hours about the abuse she had endure[d] during their fifty year marriage. Clyde had physically abused her, had numerous affairs, and had kicked her out of the house on many occasions. Now that Clyde was severely impaired, Jean talked freely about the anger she felt toward him and her desire to kill him.

Jean readily admitted to kicking him, choking him, and threatening him with a gun and knife. She had planned to kill him and was very willing to talk about it.

The case manager called the Protective Services office and found that they had been out twice before but had not intervened because Jean did not give the impression to them that she would carry out her threats. In-home services was started, and the case manager made frequent follow-up visits, encouraging Jean to use support groups and classes, but Jean did not follow through.

During one visit, Clyde was very dehydrated and needed to be admitted to the hospital. The physician was unwilling to discharge Clyde to his home, and Clyde was placed in a nursing home. This was Jean’s first time without her husband around and after one month she realized she did not have to continue caring for him. (p. 127).

Assessing situations of aggression and abuse

Many Summit participants noted that assessing situations that may involve aggression and/or abuse is a very long, complicated process. Assessment tools alone are not enough; interviews, observations, and historical information are all needed. Holly Ramsey-Klawnsnik says, “this work cannot be done quickly. It requires time, multiple people, and lots of information. It’s not something you can do in an hour.”

Summit participant Pat Anderson notes that those conducting assessments should tell those being assessed why it’s in their interest to participate. “In this population it’s hard to tease out what might be associated with an early life experience, what might be dementia, what might be long life family dynamics. It’s really a challenge. It’s hard to put people through the effort of recalling and reporting so we can gain information. We need to convince them that it’s worth the effort.”

Assessing caregivers

As noted before, caregiver perception is important. “Before we can help distressed families, we need to know their perceptions and the meaning they give to what is happening: What do they believe is in their control? What do they believe is not? What perceptions can be reconstructed? What facts will not change? And what, contextually, is blocking their management and problem-solving strategies?” (Boss, 2002, p. 13).

Assessing relationships

Holly Ramsey-Klawnsnik recommends observing “interactions between the person with dementia and the alleged abuser. How does the alleged abuser treat the elder? Some caregivers are more sophisticated and won’t misbehave in front of you, but you can get a sense that they’re acting. Emotional responses remain intact longer than the cognitive, so you may see the victim flinch or move away from the abuser. It isn’t a sure sign of abuse, but it’s a clue we look for. It’s an especially tell-tale sign if the flinch is only around one person but not others.” She goes on to advise that the person who interviews the suspected abuser should “listen not only to what the person says, but how they treat the interviewer. Some of them are abusive even to interviewers.”

Assessing persons with Alzheimer’s disease

Where the assessment of someone with Alzheimer’s disease takes place may be important. Sally Carpenter trains that persons with Alzheimer’s disease “typically function at their highest level while in their home. An interview in any other place may result in increased disorientation because their level of confusion will increase, simply by being taken out of their environment.” (p. 6).

The California Workgroup on Guidelines for Alzheimer’s Disease Management (2002) cautions, “sensory deficits can affect patient performance on assessment/evaluation scales; therefore, it is important to distinguish if low scores are due to sensory deficits or due to actual cognitive decline.” (p. 14).

Can someone believe a report of abuse from someone with Alzheimer’s? There are no definitive answers. However, Dick-Muehlke (1996) notes, “Researchers who have investigated the impact of an event’s emotional intensity on the memory of the Alzheimer’s patient have shown that impaired individuals are able to remember emotionally charged experiences much better than every day, ordinary events.” (p. 130). On the other hand, she continues, “research has also shown that persons with dementia tend to under-report, rather than exaggerate their problem. In comparison to family members and clinicians, persons with dementia consistently underestimate their difficulties in areas like depression, level of impairment, or family stress.” (p. 130).

When a person with Alzheimer’s is unable to communicate, other behaviors may signify

there's been abuse. "Problem behavior, such as wandering and aggressiveness, may be caused by dementia, but they also may reflect difficulties in the caregiving relationship. When words fail, a person with dementia will use these types of problem behaviors to communicate their needs or desires:

1. A cognitively impaired older adult may exhibit fear, become very fearful, or change his/her mood when around an abusive caregiver.
2. Researchers have shown that elder abuse victims are significantly more depressed than non-victims.
3. Abuse can also lead to an acute decline in cognitive functioning or physical health. The depression, fear, and anxiety that is associated with abuse might exacerbate the cognitive impairment or make it even worse." (Dick-Muehlke, 1996, p. 131).

Sometimes information can be obtained by joining the person with Alzheimer's disease wherever they "are." Summit participant Cathy Kehoe tells a story about an adult protective services worker who was trying to interview a woman who had dementia, had been abused, and lived in her own home. "The worker could not get anywhere with her during the first visit. The woman's history was as a very wealthy housewife. The neighbors would get together for tea in the afternoon and catch up on everyone's business. When the APS worker visited the second time, the woman was having an imaginary tea party, and the worker began to play along as one of the guests, and got the story. It was information they were able to verify elsewhere. The woman was in a familiar environment and was thinking she was talking to one of her friends."

Interviewing collaterals

"What do all the collaterals have to tell you? Professionals, other family members, paraprofessionals -- have they witnessed any derogatory treatment? Have they ever seen any physical evidence of abuse?" (Ramsey-Klawnsnik interview).

Medical and psychological exams

As noted earlier, many medical conditions can contribute to persons with Alzheimer's disease displaying problematic behaviors. The National Chronic Care Consortium and the Alzheimer's Association has set out a "Level 1" assessment for all patients suspected of having Alzheimer's disease. This includes an interview of the patient, a family interview, examination, and laboratory tests. The workup is attached as Appendix A.

When assessing pain, the American Geriatrics Society (2002) notes, "Often, older persons deny that they have 'pain'. Instead, asking your loved one whether he/she experiences 'discomfort, aching, or hurting' may result in a more truthful answer."

Assessment instruments

Three assessment instruments were initially identified as possible tools for this project. They are:

Mini Mental Status Exam (MMSE)

A sample MMSE is attached as Appendix B. It's important to note that *many* Summit participants use the MMSE, but are ambivalent about it. Summit participant Devon Christianson says, "If you ask questions right away, it embarrasses them and puts them on the spot," and reduces rapport. Carly Hellen says, "I don't like posing questions that make the person with dementia feel inadequate." Holly Ramsey-Klawnsnik concurs: "People who are having short-term memory problems but have some cognitive functioning can be humiliated by the questions and that will harm the therapeutic relationship." She also cautions, "I've seen people who lack competence who are able to pull it together under the situation of investigation and pass the MMSE." She notes that a skillful practitioner can "weave questions into the conversation that accomplish the same goal as the MMSE without being humiliating."

The California Guidelines for Alzheimer's Disease Management (2002) notes that the Cognitive Abilities Screening Instrument (CASI) may be a more appropriate cognitive assessment tool than the MMSE when assessing patients from diverse cultural backgrounds. (p. 6).

Behavioral Dyscontrol Scale (BDS)

The BDS is attached as Appendix C. The BDS, designed by Drs. Kathryn Kaye and Larry Robbins of the Geriatric Service of the Denver VA Medical Center and Jim Grigsby, Ph.D., of the University of Colorado Health Sciences Center, consists of "seven simple motor tasks, an eighth item that examines short-term memory and the ability to shift attention without becoming distracted, and the examiner's assessment of the person's ability to monitor his or her own behavior accurately." (Grigsby, 1998, p. 19). It's been demonstrated to have high internal consistency, interrater reliability, and test-retest reliability. (Grigsby, et al, 1998, p. 592). As noted earlier, this instrument measures the extent to which the person has "executive function," or the ability to form an intention and carry it out.

Problem Behavior Inventory (PBI)

This tool, attached as Appendix D, looks at 25 potential problem behaviors and asks caregivers to rate how often the behavior occurs, how much it bothers the caregiver, and the degree to which the caregiver believes the person with Alzheimer's disease can control the behavior.

Other potential assessment tools were uncovered during the course of the literature review and interviews. Only a few of these are listed here:

Neuropsychiatric Inventory Questionnaire

“Moderate evidence suggests the Neuropsychiatric Inventory Questionnaire short format (NPI-Q) is a brief, reliable, informant-based assessment of neuropsychiatric symptoms and associated caregiver distress and is appropriate for use in a general clinical practice.” (Kaufer, et al., 2000).

Columbia University Scale for Psychopathology in AD

This assessment instrument “is brief and effective in assessing psychotic symptoms, but is not appropriate for assessing changes in severity of symptoms (Devanand, 1997).” (California, 2002, p. 7).

Boundary Ambiguity Scale

This is used by Summit participant Pauline Boss. It looks at how the caregiver sees the situation. Focused on “Do I feel like I am in charge of my own life,” it may also pick up, “Do I think the person is still here?” That, she says, touches on confusion and ambiguity, “which are the strongest stressors there are.”

Pearlin’s Mastery Scale

This is a tool used by Summit participant Pauline Boss to help assess caregiver perception of the situation.

Behavior Profile and Behavior Observation Forms

Hellen (1998) has created a Behavior Profile Form and a Behavior Observation Form that can help caregivers think through what may be triggering problematic behavior. (pp. 227-234).

Cornell Scale of Depression in Dementia (CSDD)

Cornell Scale of Depression in Dementia (CSDD) was recommended by Summit participant Tim Howell as the best tool for assessing depression specifically in the context of dementia.

Intervening

It is highly likely that every situation a Dementia Response Team (DRT) is called to

assist with will require multiple interventions. Summit participant Sally Carpenter (private email dated 4/29/2002) briefly discussed one case she had where an 85-year-old, physically combative woman had a routine medical visit in which a nutritional deficit and hypothyroidism were identified. Interventions included 7 days a week of meals on wheels, 1 to 2 cans of Ensure a day, and synthroid. "Her family was provided with the 'Knack' handout and we have had many discussions on validation and redirection vs. 'pushing her buttons.' Four months ago, the family was prepared to admit her to the nursing home; today, she is still at home, functioning at her highest level with few incidents of unmanageable behavior."

Carpenter says it's important that interveners be seen as resources to the family. "I tell them the very first time I meet them, 'Tell me what you want your life to be, and I'll help you get it.' Even those who are very limited can tell you what they want." This is important in part, she says, because "many of these people are masters at manipulation and covering their deficits. We have to cut through that, but do so in a way that allows them to see us as a resource. One thing that's in our favor: so many elders *want* to talk."

Carpenter has had success recruiting volunteers to help support families caring for a person with Alzheimer's disease. "Volunteering is the American spirit. An awful lot of people are out there giving to others from their heart. That's true in these situations where we've got this vulnerable adult who has lived in the community their entire life, and is now in need. People are willing to band together to support the person. You've got a lot of people who are concerned and supportive and wanting to help. It sends a strong message that people care." She gives handouts to not only these volunteers but to all family members and "the person who delivers the groceries" to explain Alzheimer's disease, validation therapy, and other techniques for successful interaction.

Once the intervention plan is in place, Carpenter says, her mantra is monitor, monitor, monitor. "You have to build a really strong safety net for the family." They need to know "someone else cares and will stand beside them no matter what choice they make. Time after time we're defying the odds by keeping people in the community for an extra year, or two or three. Camaraderie goes a long, long way." Holly Ramsey-Klawnsnik concurs: "If you are working on a case and you've built a plan, you've got to monitor the plan and make sure it's working, not close the case and walk away."

Holly Ramsey-Klawnsnik also reminds people to remember the guardian when designing their interventions. The guardian will likely see their job as protecting their ward. "It's going to be hard for a guardian to let the ward stay with someone who has abused the ward. But if you can show the guardian how it can be done safely, the guardian will be very grateful."

Addressing Alzheimer's disease behavioral problems

In our literature review, several interventions for addressing aggression and other behavioral problems by persons with Alzheimer's disease were identified.

Hellen's Alzheimer's Disease: Activity-Focused Care (1998) contains many, many ideas for addressing behavioral problems. To distract those who are combative during certain activities, she recommends giving the person something to hold, singing with them, giving them gum or cookies, or giving them a knotted sock to unknot (among many other ideas). She also has four pages of ideas (pp. 270-273) on "activities for therapeutically reducing the prevalence, onset, or intensity of aggressive or combative behaviors."

Hellen also recommends assessing the "triggers" for behaviors and suggests looking at past roles for clues. Her book contains two forms (Behavior Profile and Behavior Observation Form) for helping with this process.

One person with Alzheimer's disease who lived in Hellen's facility had been asked to leave two nursing facilities because of disruptive behaviors during morning bathing and dressing. His daughter had been supplying plain, dark blue sweat suits with crew necks and drawstring waists to make dressing easier on the caregivers.

When the staff became aware of William's past business position [as a former executive], they changed his clothing into a shirt, tie, and pair of slacks. His perception of himself was that once more he was a business manager. He often wore a conference-type name tag and was encouraged to be 'in charge' of a team activity or project. By dressing and being supported as the leader he once had been, William felt a sense of purpose, dignity, and self-worth. He then was able to become an integral part of his peer community. (Hellen, 1998, pp. 26-27).

A tool that can make looking at past roles and preferences easier is a LifeStory book prepared by family members that includes pictures and other mementos from throughout the person's life. For more information, see Hellen (1998), pages 55-66.

Medication can be considered. "Strong evidence suggests cholinesterase inhibitors may be able to decrease the frequency of behavioral symptoms and neuropsychiatric symptoms associated with AD." (California, 2002, p 12).

A list of options generated by outside experts may be helpful. Used in a pilot study on interventions with caregivers, an Intervention Option List was generated by a team of investigators and nurses who proposed approaches to identified problems on the basis of the literature and clinical experience. The caregiving family then reviewed the list and chose one strategy – possibly modified for their specific situation – to try first. (Archbold, 1995, p. 10).

Addressing caregiver stress

Educating caregivers

One thing that was clear from the literature review and interviews is that caregivers of persons with Alzheimer's disease usually need far more education about what the disease does to its victims' brain and abilities, what caregiving does to caregivers, and ideas others have found helpful.

Boss recommends giving families caring for someone with Alzheimer's disease "as much information as possible about the kind of loss they are experiencing in order to minimize denial and enable them to begin making some choices and decisions. For most couples or families, this kind of therapy – often called the psycho-educational approach – helps to unfreeze the coping process." (1999, p. 91). She specifically recommends discussing the effects unresolved grief has on family members. (1999, p. 50).

Summit participant Carly Hellen calls this process empowering the caregiver. "We've got to empower the caregiver to think for themselves. They've got to be able to problem-solve. They've got to have the confidence that they can read a situation and respond. They also need skills in reading the patient: What's dad doing when he *starts* to get upset, and how can I refocus him then before he blows up?"

Caregiver support groups

Oftentimes caregiver support groups are recommended for educating caregivers and reducing their stress, but Kilburn (1996) cautioned, "mere contact with a support group has no relationship with caregivers' violent ideation. Quality of support is more important. Though contact with support groups is recommended by Suitor and Pillemer (1992), it is only when significant relationships are formed with other group members that a lower probability of fear of becoming violent is generated." (p. 79).

Boss, on the other hand, notes that connecting with others is very helpful to those experiencing ambiguous loss: "Using the reactions of others – their looks, their words, their emotions, and their touch – we construct new realities. Even family members deeply entrenched in their loss and resistant to change will show a greater willingness to accept a revised relationship with a sick spouse or parent – or an absent child – once they have reached out to others. Overcoming the solitude of ambiguous loss is the first step on the road to healthy change." (1999, p. 103).

Changing perception

Boss (1999) talks about a wife caring for a husband with Alzheimer's disease who continuously wanted sex. Since he no longer knew who she was, she found these demands very distressing. "When interviewed a few months later, this same woman

appeared serene. I asked her what had changed. She reported that one day a solution to her problem had suddenly occurred to her. She went into the bedroom, took off her wedding ring, and put it away in her jewelry box. After that, she said, she knew how to manage her husband's behavior. She no longer saw him as her husband but simply as someone she loved and would care for. Just as she had done with their children years ago, she set boundaries, moving him to a separate bedroom and directing his daily routines. The stress level for both patient and caregiver went down. On the day her husband died, two years later, she went back to her jewelry box, took out her wedding ring, and placed it back on her finger. 'Now I am really a widow,' she said, 'not just a widow waiting to happen.'" (p. 108).

Boss says you can simply ask caregivers, "How do you see this?" "It's easier than you think. Then you can tailor-make the parameters for intervention." Those interventions must be tailored, however. She has found that "individuals are stimulated to change by different things. For people who are accustomed to having some control over their lives, insight appears to help; such people want to understand 'why,' to penetrate the deeper meaning of an experience before they risk doing something different. But for others, insight is gained experientially, not cognitively...[they] have to experience a phenomenon before they can understand it." (1999, p. 109).

Self-help books

Self-help books may be very useful for some caregivers. There are many designed specifically for the caregivers of persons with Alzheimer's disease, and there are others that may help a caregiver cope with a particularly thorny problem. One such book was recommended by Summit participant Janice Griffin: *The Courage to Heal: A Guide for Women Survivors of Sexual Abuse*. The authors weave personal experience with professional knowledge to show the reader how she can come to terms with her past while moving powerfully into the future. They provide clear explanations, practical suggestions, a map of the healing journey, and many moving first-person examples of the recovery process drawn from their interviews with hundreds of survivors. Sections include: "Taking stock," which outlines the effects of child sexual abuse and the ways women cope over time; "The healing process," which explores each stage from the decision to heal and remember through breaking silence, knowing it was not your fault, nurturing the inner child, through grief and anger, to resolution and moving on; and "Changing patterns," which offers in-depth guidance for shifting self-defeating patterns in specific areas of one's present life, including self-esteem, intimacy, sexuality, and dealing with families. It also includes "Supporters of survivors," which provides insight and strategies for partners and families of survivors, and counselors; "Courageous women," which profiles survivors; "Honoring the truth," which explores the "false memory" argument; and a resource guide.

Enrich the caregiving experience

Summit participants Carly Hellen and Theresa Harvath both recommend addressing

what the caregiver is getting out of the situation. Hellen (1998) says, "caregivers seek to experience their own involvement with the resident as a purposeful, meaningful activity." (p. 8). Harvath agrees: "Another piece that's important and not focused on much: how can we enrich this caregiving situation? Caregivers who do well have opportunities to do something they enjoy for or with the care receiver." She cites an example a case in which the caregiving daughter reads the newspaper during the day while her mother is at adult day care, but allows the mother to read the news to her again at night so her mother has the pleasure of telling her something "new." Other possibilities are going out for dinner or doing something for the care receiver that both can enjoy. She says to ask, "What did you used to enjoy? Can you do that now? These things help remind you why you love this person."

Shifting the caring dyad

Many interventions focus on reducing tensions between the caregiver and carereceiver. Some of these include the following.

Redefine the behavior as activity

Hellen (1998) says, "Considering and defining a reaction or response as an activity, rather than a problem, appear to give both the resident and the caregiver permission to be creative and flexible." (p. 1). She goes on, "If caregivers can 'frame' or acknowledge a resident's behavior, such as pacing, as the resident's activity rather than an annoying negative behavior, they are more capable of releasing former expectations and open to redefining parameters of acceptance." (pp. 7-8).

Validation Therapy

Validation Therapy is often discussed as the opposite of trying to make a person with Alzheimer's disease understand what's really true about their current reality. Developed by Naomi Feil, it encourages the person with dementia to express his/her reality -- whatever that reality might be -- and assisting that person to deal with his/her reality in a comfortable and supportive environment. One practitioner boiled the idea down to five points.

1. Get into the person's time frame. He or she may be back in time when he or she had small children, or when he or she was working....
2. Understand what he/she is feeling and expressing. It is very real to him/her. Take him/her very seriously. He/she will pick up on it if you don't.
3. Respond to the feelings. You may even say, "You look so upset."
4. Reassure them. Move the conversation on to happy times, if possible: "I bet you were a great mother!" "You must be very proud of your boys!" "What a hard worker you are!" Guide them into reminiscing about their past.

5. Pay attention to their needs, meet them if possible, and move them on to another frame of mind. Sometimes all a person needs is love and attention. (Platt, 2001).

In his work, Kunz (undated) recounts a conversation he had with a person with late-stage Alzheimer's disease. Using a validation approach he concludes, "it is obvious that Viola needs to believe that her parents are alive. She talks from a child's perspective and in a child-like tone. She needs their love and to believe that they are proud of her. She leads the interviewer exactly to what she needs: validation that she is a good person and a good daughter. Doing so caused her to smile and obviously boosted her self-esteem and quality of life for at least the moment." (p. 25).

Kunz (undated) also reported on a study that found that "training caregivers in reminiscence work and the use of such activities greatly enhanced the home environment." (p. 9).

Change the environment

Many times, the tension between caregiver and care receiver can be reduced by fairly simple changes in the environment. Summit participant Theresa Harvath gives three examples. In one case, a person with dementia wouldn't go to bed because it was impolite to do so when guests were present. The "guests" she saw was herself in the living room mirror. When the caregiver got rid of the mirror, the woman was willing to go to bed. In another case, a woman with Alzheimer's disease wanted to wash dishes all the time. But the low-income household couldn't afford all the dishwashing liquid. They ended up keeping very diluted bottles of dishwashing liquid available for her, along with lots of dirty dishes. In this same case, the elder always wanted to wear her Sunday best. They moved those clothes into the caregiver's closet so the elder didn't see them and therefore be tempted to put them on.

Addressing abuse

Ramsey-Klawnsnik's typology of abusers suggests determining what "type" an abuser is before deciding whether the caregiver can remain with the care receiver if certain supports or interventions are made, or whether the caregiver is basically irredeemable and should perhaps be prosecuted.

Plan for safety

Either way, the safety of the victim(s) of the abuse must be at the forefront. "Safety planning" is a term that is used in different ways by different professionals involved with dementia and abuse. For some, it refers to planning how to keep a person with dementia safe at home, using such techniques as modifying or removing appliances that could start a fire, throwing out spoiled food, etc. (An example of this type of safety

planning is contained in the document sent pre-Summit, “Home and Community Based Model for Dementia Care Planning.”)

With victims of domestic violence who are cognitively intact, another type of safety planning is required. This sort of safety planning is a proactive process where victims determine a plan of action in a variety of situations (e.g., during an abusive incident, in public, in their home). Safety planning helps develop protective strategies in advance of potentially dangerous situations. The process enhances future safety, gives victims ideas of strategies to use, and returns some control/decision-making in their lives. During the process, the victim envisions how s/he might remain safe in his/her particular circumstance. If s/he has chosen to leave his/her abuser, where will s/he go? What does s/he need to bring? If s/he decides to return to the relationship, what can s/he do when another incident occurs?

Older victims of domestic violence, like younger victims, may be in danger of serious injury or death if they choose to stay or are trapped in abusive relationships. In fact, known domestic violence is present in about one-third of the cases of homicide/suicide involving elderly (Cohen, 1998). Research indicates that the lethality of the perpetrator’s violence often increases if the abuser believes that the victim has reported the abuse, has left, or is about to leave. (Campbell, 1986; U.S. Dept. of Justice, 1992, p. 149). Therefore, safety planning is crucial. The Wisconsin Coalition Against Domestic Violence has a safety planning brochure which addresses older victim needs and a booklet on safety planning for people with physical disabilities.

Think about double victims

That’s what Summit participant Devon Christianson calls cases of longstanding domestic violence. “If it’s longstanding domestic violence, we need to approach it differently because there are double victims. These are the most dangerous kind of situations because they’re going to repeat themselves over and over and over. You can’t say to them, ‘If you change this, you’ll have a whole new life,’ like you can to a younger person. The older victim is much harder to convince that she doesn’t have to live like this anymore. What do we offer them as incentive to change?”

Summit participant Deb Spangler talks about two victims in another way: “If you’re talking about retaliation by a caregiver toward an abuser, you need to take into account the years of abuse and the trauma suffered by the victim, and their impact.”

Watch for victim-blaming and self-blaming

As noted earlier, Boss says, “if a person believes in a just world and values mastery, he or she may also believe it is not logical for bad things to happen to good people and will therefore blame the victim.” (2002, p. 146). Interveners must be careful not to fall into this trap. They also need to watch for victim-blaming by the victim herself. Summit participant Janice Griffin spoke of a non-demented sexual assault victim who blamed

herself in part because of how the interventions turned out:

One client had been sexually assaulted when she was in her 70s. She lived with her husband at the time. As a result of the assault, she went through a really deep depression. She was placed in an assisted care facility. Her husband could not take care of himself, so he, too, was placed in a care facility. She and her husband were separated while she was in the care facility. It might have been the straw that broke the camel's back. She blamed herself because her assault caused her to be separated from her husband. She felt awful about it and was severely depressed following the assault and separation.

Summit participant Lauri Nichols talked about another case where the victims ended up feeling somewhat blamed for what happened. In this case, children of a caregiver were sexually abused by a person with dementia. They were told, “the fellow didn’t really mean it, he was sick.”

Make sure other professionals know what they need to know

Summit participant Janice Griffin told of another sexual assault case involving an older woman. It was an anal rape by a neighbor, and the woman ended going into a hospital. Unfortunately, while she was there she developed constipation and the staff, which didn’t know about the assault, gave her an enema. “She started to deteriorate after receiving this treatment.” Griffin notes the woman had a considerable amount of depression, although she didn’t know if it was caused by the abuse or predated it. The woman did “experience a huge failure to thrive, which was directly related to the assault,” Griffin says. She died shortly thereafter.

Sexuality, sexual abuse and assault, and consent issues

Sexual behavior involving persons with Alzheimer’s disease seems to be an especially complex issue for interveners. It is a common assumption in our society that older people do not engage in sexual activity. This, plus a tendency to dislike thinking about “people of my (grand)parents’ generation” having sex, may make it difficult for interveners to address issues pertaining to sexual behavior.

Similarly, interveners may resist thinking about sexual assault. “Sexual assault happens a *lot* more than people are aware of,” Summit participant Tiffany Lodholz says. Even when they do accept the reality of sexual abuse of elders, Summit participant Maria Ledger notes, they still may not see it correctly. “In the cases the Department on Aging sees, the majority of abusers were family members. It is usually presumed that it must be someone else.” Tiffany Lodholz confirms that: “people hold a myth that sexual assault is always stranger rape.”

Caregivers also find sexuality issues very difficult to deal with: as noted previously, one

study found that caregivers rated “being sexually inappropriate” the care receiver behavior they found *most* problematic.

Ability to consent to sexual activity

The ability to consent to sexual activity is a huge question for spouses, caregivers, and interveners. Spouse caregivers may have many questions and emotions about sexual behavior with their demented spouse. Summit participant Tiffany Lodholz discussed a case where a man did not want to violate his demented wife’s rights, but she would have some good days and some bad days...how did that play into her ability to consent?

Although this is an evolving area with no absolutes, Teitelman and Copolillo (2001) suggest the following questions be used as guidelines in determining a person’s ability to consent to sexual activity.

- Person’s awareness of relationship
 - Does person know who is initiating sexual contact?
 - Does client believe other person is a spouse or partner (when he or she is not)?
 - Can person articulate what level of sexual intimacy he or she would be comfortable with?
- Person’s ability to avoid exploitation
 - Is behavior consistent with formerly held beliefs/values?
 - Does person recognize concepts of choice and voluntariness?
 - Does person have all information needed to make a decision?
 - Does person have guardian?
- Person’s awareness of potential risks
 - Does person realize sexual contact may be time-limited?
 - Can person describe how they will respond if and when contact ends?
 - Is person aware of any potential physical or emotional harm? Can she or he take precautions against such risks (e.g., prevention of sexually-transmitted diseases)?

One publication devoted specifically to these issues is Ballard and Poer’s (1993) “Sexuality and the Alzheimer’s Patient.” Among other topics, Ballard and Poer address at length questions well spouses may have about the appropriateness of sexual activity with their demented spouse. Hellen (1998) also includes a chapter on intimacy and sexuality, including many ideas of how to use appropriate touch to meet the intimacy needs of persons with Alzheimer’s disease.

Sexual abuse

Whether behavior is sexual abuse can be murky for reasons beyond capacity to consent. Summit participant Pat Anderson notes, “Some people feel they were sexually abused or assaulted within their marriage. Part of these feelings arose

because they were Catholic and believed that sexuality without the goal of conception was wrong. So if there was sexual activity in 60-90 year olds, some perceived this to be abusive.”

More clear-cut cases are those in which it is obvious the sexual activity was perpetrated by an abuser solely for the abuser’s pleasure or feelings of power and control, and consent was a non-issue. However, interveners sometimes conceive of such abuse too narrowly. Summit participant Tiffany Lodholz divides sexual assault into hands-on assaults, which tend to use force, touching, and rape-type assault, and hands-off offenses such as voyeurism, sexual harassment, and forced viewing of pornography. She also includes what she calls “harmful genital practices,” such as using a spoon to loosen constipated bowels or rubbing too hard with washcloths.

Sexually inappropriate behavior

Because caregivers’ perceptions are so key to their feelings of stress, it’s important to assess whether behavior perceived as inappropriately sexual is sexually related at all. Removing clothing may be related to a need to use a bathroom or wearing clothes that feel uncomfortable, for instance. (Ballard, 1993, p. 8).

Caregivers may inadvertently trigger sexual responses during activities of daily living; Hellen’s (1998) chapter on intimacy and sexuality discusses several such possibilities and how they can be addressed.

Adult child caregivers may be especially stressed by a demented parent’s sexual advances. If the caregiver is the same gender as the parent’s deceased spouse, pointing out the physical similarities and reviewing how the person with Alzheimer’s may be living in the past may help the caregiver cope. Certain medications might increase the libido, so that possibility should be looked into. (Hellen, 1998, p. 317).

Both Ballard and Poer’s (1993) Sexuality and the Alzheimer’s Patient and Hellen’s (1998) intimacy chapter contain many suggestions for redirecting the behavior of individuals with Alzheimer’s disease who are perceived as being sexually inappropriate.

Dementia Response Teams

One of the goals of the overall Wisconsin Bureau on Aging and Long Term Care Resources project is to develop Dementia Response Teams (DRTs), which will utilize a protocol developed out of this Summit. Many Summit participants discussed challenges these DRTs may face, and offered ideas for the DRTs to consider.

Meshing perspectives

One of the challenges facing multidisciplinary teams is building upon and reconciling

different professions' viewpoints. The following chart prepared by the Wisconsin Bureau of Aging and Long Term Care Resources looks at three professions' models of what causes aggression and what to do when it occurs.

| How Three Different Systems View “Aggressors” Wisconsin Models Operating Separately | | | |
|--|--|--|--|
| | Elder Abuse | Domestic Violence | Dementia Care |
| Basic Premise | Field historically operated from belief abuser acts primarily from “caregiver stress” based on dependency of victim on abuser. | Believes aggressor acts from ongoing abuse of power and control and sense of entitlement. | Believes aggression is part of the illness, person is not responsible for his/her own behavior due to disease process leading to incompetence. |
| Application | Protective services based | Law enforcement based | Medical-Social model based |
| Intervention | Intervenes by supporting the “stressed aggressor” to prevent further abuse. | Intervenes by arresting the aggressor and holding him/her legally accountable. Domestic violence programs focus on work with victims. Batterers may attend a separate treatment program. | Intervenes by assessing and treating person, and referring to services. Educates and supports family to remain involved in person’s care. |
| Problem with Approach | If not a stressed caregiver, allows an aggressor power and control to continue with abusive behavior. | Inappropriate application of domestic violence laws treats incompetent aggressor with dementia as a criminal. Allows no assessment, support or intervention. Exacerbates situation. | Does not recognize dynamics of family violence, its ongoing patterns, or impact of historical traumatic events the person with dementia has experienced. |

Some of the difference in perspectives is due to the history of how the various fields developed. Nerenberg (2002) writes, “Early studies portrayed the ‘typical’ elder abuse case as one in which a frail older woman was abused by a well-meaning but understandably overstressed caregiver. Some researchers and professionals in the field of elder abuse prevention and adult protective services have blamed this persistent characterization, now known to be inadequate, with distorting the public’s understanding of elder abuse and steering attention away from more promising lines of inquiry. Some believe that this profile accounted for the fact that elder abuse was viewed for many years strictly as a social service problem that could be addressed most effectively through social service interventions; today, many forms of abuse and neglect are resolved through legal interventions as well.” (p. 3).

She continues, “From the other end, professionals in the field of dementia care have tended to de-emphasize violence in caregiving relationships, and hesitated to apply the

label of elder abuse to mistreatment by family caregivers. It is understandable that some view elder abuse as an inadequate description for the complex dynamics and interactions that often accompany aggression in caregiving relationships, particularly when the aggression is mutual or interactive. Some fear that focusing on caregivers' aggression, without considering the broader context in which it occurs, may lead to unfair punitive responses." (p. 3).

Tiffany Lodholz is one of several Summit participants who discussed the challenges of working with professionals who come from differing expectations and roles. She says that in such situations, "someone might be more victim centered whereas people like law enforcement might take the view of there being a 'bad person' who needs to be put in jail. A facility administrator might be looking at liability. It's hard to get everyone to see other perspectives. We all have different missions and perspectives." In the multidisciplinary team she works with they have tried to resolve the differences by focusing on common goals. "We are mainly concerned with honoring different points of view, being aware of re-traumatizing the victim, endangering safety by reporting, and making sure we take things on a case by case basis."

Specific professions' needs

Specific professions were identified as having specific needs for training or other assistance.

- Law enforcement. Several Summit participants discussed specific law enforcement needs. William Hanrahan said, "police have no idea where to go with people with dementia, what to do with them. Law enforcement is a reactive body rather than being proactive. They lack recognition that the problem [involving someone with dementia] does not go away if they don't do anything." He also suggested they may need specific training on how to tell normal aging from abuse and neglect: "They see the signs [of abuse] as part and parcel of the aging process." Summit participant Janice Griffin believes that law enforcement may need more help in ensuring shy or quiet sexual assault victims are referred to the Rape Crisis Center. She fears older persons may be more "compliant" and hence get referred less.
- Mental health professionals. Summit participant Timothy Howell notes that although mental health professionals are often involved in cases involving people with Alzheimer's disease and aggression or abuse, "they're not properly trained for this population."
- District attorney. Summit participant Pat Anderson feels that the DA's office has been difficult for her community to work with because she feels they are not informed on how to give specialized support to the elderly, and they don't have sufficient time allotments to work with elders. However, she notes her DA's office has recently hired an elder victim specialist.

- Courts. Summit participant Devon Christianson notes that courts want *proof* a person with Alzheimer's disease who is alleged to have done something doesn't know what he's doing. Participant Marti Sanville says, "the legal system doesn't have the expertise to make good assessments and good choices about elders" who are demented.

Training topics

All professionals involved with persons with Alzheimer's disease might benefit from training on body language and other self-presentation issues. Hellen (1998) points out, "it appears that as the resident's ability to use meaningful words diminishes, his or her intuition and ability to 'read' another's feelings increases. Sensitivity to the emotional climate intensifies. A caregiver who appears tense and nonaccepting is 'sized up' by the resident immediately. The resident often responds to this person with increased anxiety, which may lead to combativeness or other catastrophic reactions." (p. 77).

Summit participant Betsy Abramson took a crack at what should be included in a training manual for DRTs:

- What is the issue, what is the problem?
- Case examples – real folks and examples of how their needs were responded to. Very specific situations, some with happy endings and some with bad outcomes.
- Interview techniques: dealing with family or individuals (including how to deal with comments like, "He didn't really mean it" or "What the hell do you mean!?!?" How to sensitively meet families wherever they are).
- Explain the law about mandatory arrest in situations of domestic violence – how things are or aren't relevant.
- Resources.
- Background materials.
- Journal articles.
- Protocols and assessment tools – for social worker-type involvement, law enforcement, and health care professionals.

Consultation model of training

Summit participant Timothy Howell is working on a system where geriatric psychiatrists have ongoing relationships with law enforcement, emergency rooms and multidisciplinary teams in a "consultative liaison" model. He notes that if you debrief people over a long period of time, "their expertise rises dramatically," whereas one-time trainings seldom produce lasting change.

System issues

Summit participants were concerned about a number of systemic issues. Anthony

Braus notes, “someone has to implement after care decisions are made. Some real structural change is needed. We already have case managers running around trying to coordinate these things, but the system doesn’t exist to handle the needs. Roughly speaking, there doesn’t seem to be a continuum of care, a home care system, and a political system that supports those things. The question is, do we have the resources to implement whatever plans or recommendations that the DRT makes? The DRT is only part of the continuum of care. There are all the other pieces that are also needed to get a good continuum.”

Responsibility

In her county’s experience trying to address the same issues being addressed by this Summit, participant Mary Bouche noted that primary barriers are funding and which agencies are ultimately responsible for providing services. When that is determined, she notes, the next question is, “do these people have the technical expertise they need to be providing these services?”

Prioritization

In Pat Anderson’s area, the crisis unit prioritizes suicides and homicides, meaning that even when situations are reported early, they are often left unaddressed until they escalate. “We need earlier identification and capacities to deal with these people,” she concludes.

Advocacy

Devon Christianson says that for DRTs and similar systems to work, you have to have an advocate. “I can talk really loud and they can’t fire me. Can that happen in other counties where you don’t have an independent advocate? Progress in our county wouldn’t have happened without the advocacy. So you either have to have grassroots advocacy, or the state has to mandate the changes.”

Legal barriers

Anthony Braus notes, “another pitfall I run up against is legal issues. We don’t really have adequate elder law to allow for certain interventions. As one example, you can’t hold substance abusers (in an institution) once they’ve sobered up.”

Funding

Timothy Howell notes that while intervening in a comprehensive way in these situations could be expensive, “every day you keep a person with dementia out of the hospital, you save \$1,000 – that would pay for a lot of consultation time. Cost-shifting is a problem, though. If someone goes into the hospital, Medicare covers it. So the trick is identifying which organizations have some incentive to support intervention. It’s labor

intensive, but it can pay off in the long run.” Holly Ramsey-Klawnsnik also pointed out the possible cost savings: “it’s much cheaper to do a thorough investigation of a case and help an elder than to put her in a nursing home.”

Lack of batterers’ treatment programs

Maria Ledger notes that there is not much available for older abusers. “No one is quite sure what to do with an abusive old man, let alone an abusive woman.”

Questions for later

Clearly, the task of understanding all that is happening in situations involving someone with Alzheimer’s disease and abuse or aggression is huge. Many of the answers we seek simply don’t exist yet. Nevertheless, it’s important to enumerate the questions as a guideline for further work. Among the questions Summit participants would like to have answered that we will probably not be able to address in depth (if at all) at the Summit itself are:

- How do we educate the public about these issues? (Sager)
- Is there a tool that can help us assess how reliable and accurate are the reports people with Alzheimer’s give of their early life experiences? (Anderson)
- How do we help the nursing homes with aggressive residents, particularly given the pattern that’s been entrenched for 10 to 15 years that it’s *never* appropriate for a nursing home resident to be put in the mental health system. “Nursing homes do need a psychiatric evaluation and medication help, and there’s no place for them to get it.” (Christianson)
- Nursing homes are often in what feels to them like a double bind. They aren’t allowed to contain a person’s aggressive behavior, but then they are cited when the person becomes aggressive. How can we help them? (Lewis)
- Several participants pointed out that once a person with Alzheimer’s disease who has a behavioral issue is placed anywhere else temporarily, the nursing home often refuses to take her back. What can we do in these situations?
- How do we help staff of nursing homes who are being abused and sexually harassed by persons with dementia? An example of this is a resident calling a staff member a “cunt.” “These issues need to be dealt with, not just attributed to the resident’s dementia and not addressed.” (Griffin)
- How can we train staff in nursing homes that “when a person is talking about sexual abuse or talking about something specific or sexual, it’s important for the

staff to hear it and not ignore it or discount the stories that are being told.” (Griffin)

- Is there a way to create a model or stages of abuse in different stages of life? In other words, if someone is sexually abused as a child, is it different than if they were abused at 50 years old or 70 years old? (Anderson)
- Does abuse in earlier life have anything to do with dementia in later life? (Griffin)
- Summit participant Jeff Lewis would like to see regional specialty facilities modeled on Toronto’s specialty hospital for developmentally disabled persons. “The design recognizes that many people may need to stay longer in the hospital than non-DD people, or they may need more structured care after release. But the goal is to work with them and get them back to their community and their home as soon as possible, in ways that are healthy for them. The problem with most hospitals is that there is a mixing of people who are really vulnerable with people who are not so disruptive. When people with special needs need more assistance, it takes care away from others. We need to balance the level of care needed with the amount of staff necessary to accommodate those needs.” How do we make that happen?
- People with Down’s Syndrome *frequently* develop Alzheimer’s disease. “There is a direct correlation between Alzheimer’s disease and Down’s Syndrome. All people over age 40 with Down’s have plaques that have been tangled. The pathology is there for Alzheimer’s disease in Down’s Syndrome folks, although not all Down’s Syndrome folks show behavioral signs. Now that we take better care of people with Down’s so they live longer, we are seeing more clients who have Alzheimer’s disease.” How would the work of the DRTs need to be adapted for people with Down’s Syndrome? (Schlimmen)

Bibliography

Abramson, B. Interview with Michael Munson, May 2, 2002.

Allers, C.T.; Benjack, K.J.; Allers, N.T. (1992) Unresolved Childhood Sexual Abuse: Are Older Adults Affected? Journal of Counseling & Development, 71: 14-17.

The American Geriatrics Society Foundation for Health in Aging (2002). Assessing Pain in Loved Ones with Dementia: A Guide for Family and Caregivers (brochure). http://www.healthinaging.org/public_education/pain/pain_dementia.pdf [Note: misspelling in URL is correct]

American Medical Association (1999). Diagnosis, Management and Treatment of Dementia: A Practical Guide for Primary Care Physicians. Chicago.

Anderson, P. Interview with Michael Munson, May 10, 2002.

Archbold, P.G.; Stewart, B.J.; Miller, L.L.; Harvath, T.A.; Greenlick, M.R.; Van Burean, L.; Kirschling, J.M.; Valanis, B.G.; Brody, K.K.; Schook, J.E.; Hagan, J.M. (1995). The PREP System of Nursing Interventions: A Pilot Test with Families Caring for Older Members. Research in Nursing & Health, 18:3-16.

Archbold, P.G., Stewart, B.J., Greenlick, M.R., & Harvath, T.A. (1992). "The clinical assessment of mutuality and preparedness in family caregivers to frail older people." In S.G. Funk, E.M. Tornquist, M.T. Champagne, and R.A. Wiese (eds.), Key aspects of elder care: managing falls, incontinence and cognitive impairment (pp. 328-339). New York: Springer Publishing Company.

Ballard, E.L.; Poer, C.M. (1993) Sexuality and the Alzheimer's Patient. Durham, North Carolina: Duke University Medical Center.

Bass, E.; Davis, L. (1994) The Courage to Heal: A Guide for Women Survivors of Child Sexual Abuse. Harper Perennial.

Baxter, E.C.; Schroeder, J.E. (1996). Persons with Dementia: At Risk and Vulnerable. In Silent Suffering: Elder Abuse in America, (pp. 124-128). Long Beach: Archstone Foundation.

Boss, P. (2002). Family Stress Management: A Conceptual Approach (2nd edition). Thousand Oaks: Sage Publications.

Boss, P. (1999). Ambiguous Loss: Learning to Live with Unresolved Grief. Cambridge, Massachusetts: Harvard University Press.

Bouche, M. Interview with Loree Cook-Daniels, April 24, 2002.

Brandl, B; Cook-Daniels, L. (in press) Domestic Abuse in Later Life: Research Review and Charts.

Brandl, B.; Raymond, J. (1997) Unrecognized Elder Abuse Victims: Older Abused Women. Journal of Case Management, 6(2): 62-68.

Braus, A. Interview with Loree Cook-Daniels, May 1, 2002.

California Workgroup on Guidelines for Alzheimer's Disease Management (2002). Guidelines for Alzheimer's Disease Management. www.alzla.org/medical/FinalReport2002.pdf.

Campbell J. (1986) Nursing Assessment For Risk of Homicide with Battered Women. Adv Nurs Sci., 8(4): 142-147.

Carpenter, S. Interview with Loree Cook-Daniels, April 29, 2002.

Carpenter, S. Email to Loree Cook-Daniels dated 4/29/2002.

Carpenter, S. Training notes, crisis Intervention with the Elderly. (undated).

Chronic Care Networks for Alzheimer's Disease Initiative (2001). Tools for the Assessment and Treatment of Dementia in Managed Care Settings. National Chronic Care Consortium and the Alzheimer's Association. www.nccconline.org/pdf/CCNADtools.pdf.

Cohen, D. et al (1998). Homicide - Suicide in Older Persons. The American Journal of Psychiatry, 155(3): 390-396.

Coyne, A.C. (2002). The Relationship Between Dementia and Elder Abuse. Geriatric Times, 2(4); www.medinfosource.com/gt/g010715.html.

Coyne, A.C.; Potenza, M.; Berbig, L.J. (1996). Abuse in Families Coping with Dementia. Aging Magazine, 367:93-95.

Dick-Muehlke, C.; Yang, J.a.; Yu, D.; Paul, D.M. (1996). Abuse of Cognitively Impaired Elders: Recognition and Intervention. In Silent Suffering: Elder Abuse in America, (pp. 129-133). Long Beach: Archstone Foundation.

Feinberg, L.F. (2001). Systems Development for Family Caregiver Support Services. Paper prepared for the U.S. Administration on Aging Caregiver List Serv.

Flaherty, G. and Raia, P. (1994). Beyond Risk: Protection and Alzheimer's Disease. Journal of Elder Abuse & Neglect, 6(2): 75-93.

Grabmeier, J. (2001). Former Caregivers Still Show Psychological Ills Years After Caregiving Ends. Ohio State University Research Communications. www.osu.edu/researchnews/archive/formcare.htm.

Griffin, J. Interview with Michael Munson, April 22, 2002.

Grigsby, J.; Kaye, K.; Shetterly, S.M.; Baxter, J.; Hamman, R.F. (2000). Prevalence of Disorders of Executive Cognitive Functioning Among the Elderly: Findings from the San Luis Valley Health and Aging Study. Unpublished paper.

Grigsby, J. (1998). Assessing Behavioral Self-Regulation Among Older Persons Plays Important Role in Overall Neurologic Evaluation. Victimization of the Elderly and Disabled, July/August 1998: 19-20.

Grigsby, J.; Kaye, K.; Baxter, J.; Shetterly, S.M.; Hamman, R.F. (1998). Executive Cognitive Abilities and Functional Status Among Community-Dwelling Older Persons in the San Luis Valley Health and Aging Study. JAGS, 46: 590-596.

Grigsby, J.; Kaye, K.; Robbins, L.J. (1995). Behavioral Disturbance and Impairment of Executive Functions Among the Elderly. Archives of Gerontology and Geriatrics, 21: 167-177.

Harris, S. (1996). For Better or for Worse: Spouse Abuse Grown Old. Journal of Elder Abuse & Neglect. 8(1): 1-33

Harvath, T.A. (1994). Interpretation and Management of Dementia-Related Behavior Problems. Clinical Nursing Research, 3(1): 7-26.

Hellen, C.R. (1998). Alzheimer's Disease: Activity-Focused Care, (2nd edition). Boston: Butterworth-Heinemann.

Kilburn, J.C. (1996). Network Effects in Caregiver to Care-Recipient Violence: A Study of Caregivers to Those Diagnosed with Alzheimer's Disease. Journal of Elder Abuse & Neglect, 8(1): 69-80.

Kohlenberg, C. (2002). Interview with a Medication Specialist. Connecting Minds – Dementia Care Newsletter, Wisconsin Bureau of Aging and Long Term Care Resources, 2: 4-5.

Kunz, J.A. (undated) Targeted Reminiscence Interventions for Older Adults with Dementia. Final draft to be published in Journal of Geriatric Psychiatry.

Ledger, M. Interview with Michael Munson, May 2, 2002.

Lewis, J. Interview with Michael Munson, May 2, 2002.

Lodholz, T. Interview with Michael Munson, April 24, 2002.

Miller, L. (2001) Treating & Compensating Victims of Post Traumatic Stress Disorder: Interview with Laurence Miller, Ph.D. Nexus, 7(3): 1+.

Montgomery, R.J.V.; Kosloski, K.D. (undated) Change, Continuity and Diversity Among Caregivers. Unpublished paper.

Mouton, C. et al. (1999). The Associations between Health and Domestic Violence in Older Women: Results of a Pilot Study. Journal of Women's Health & Gender-Based Medicine, 1(9): 1173 – 1179.

Nerenberg, L. (2002). Preventing Elder Abuse by Family Caregivers. Washington, D.C.: National Center on Elder Abuse.

Phillips, V.L.; Egner, A.M. (undated) Developing a Case Management Tool to Assess Problem Behaviors in Demented Elders. Unpublished paper.

Platt, V. (2001). Innovations in Recreation: Ask the Consultant. <http://www.innovationinrecreation.com/ask.htm>.

Ramsey-Klawnsnik, H. (2000). Elder-Abuse Offenders: A Typology. Generations, 24(2): 17-22.

Reines, M.; Lawrence, B.; Beall, S.; Kehoe, C. (2002) Home and Community Based Model for Dementia Care Planning. Madison: Alzheimer's Association – South Central Wisconsin Chapter, the Wisconsin Alzheimer's Institute, and the Wisconsin Bureau of Aging and Long Term Care Resources.

Sanville, M. Interview with Michael Munson, May 3, 2002.

Schlimgen, B. Interview with Michael Munson, May 9, 2002.

Teitelman, J.L.; Copolillo, A. (2001). Sexual Abuse in Persons with Alzheimer's Disease: Detection and Appropriate Response. Unpublished paper.

Torum, S. Interview with Michael Munson, April 23, 2002.

U.S. Department of Justice (1992). Criminal Victimization in the United States. Washington, DC: Bureau of Justice Statistics.

Wolf, R. (1998). Caregiver stress, Alzheimer's Disease, and Elder Abuse. American Journal of Alzheimer's Disease, March/April 1998: 81-83.

Wolf, R. (1995). A Brief Look at: Elder Abuse & Alzheimer's Disease. NCEA Exchange, 2(2): 10-12.

Yaffe, K.; Fox, P.; Newcomer, R.; Sands, L.; Lindquist, K.; Dane, K.; Covinsky, K.E. (2002). Patient and Caregiver Characteristics and Nursing Home Placement in Patients with Dementia. JAMA, 287(16): 2090-2097.

Appendix A: Level One Work-up

Mini mental first page

Appendix B: Mini-Mental Status Exam

Mini-mental 2nd page

Appendix C: Behavioral Dyscontrol Scale

BDS insert page 1

BDS insert page 2

Appendix D: Problem Behavior Inventory

PROBLEM BEHAVIOR INVENTORY (BPI)

Ask the Caregiver These Questions:

| Have you had problems in the past six months with the client: | How often does the behavior occur? | How much does the behavior bother you as a caregiver? | To what degree do you think that the client can control his or her behavior? |
|--|--|---|---|
| | 0 = has never occurred 1 = has occurred before, but not in the past week 2 = once a week 3 = more than once a week 4 = at least daily 9 = don't know/not applicable | 0 = not at all 1 = a little 2 = moderately 3 = very much 4 = extremely 9 = don't know/not applicable | 0 = not at all 1 = a little 2 = some 3 = a lot 4 = completely 9 = don't know |
| Losing or misplacing things | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Accusing others of stealing | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Hoarding or hiding things | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Appearing sad or depressed | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Crying or being tearful | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Being uncooperative or refusing to take medications | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Being uncooperative when you try to help with transfers | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Being uncooperative when you try to help with dressing | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |

| Have you had problems in the past six months with the client: | How often does the behavior occur? | How much does the behavior bother you as a caregiver? | To what degree do you think that the client can control his or her behavior? |
|--|--|---|---|
| | 0 = has never occurred 1 = has occurred before, but not in the past week 2 = once a week 3 = more than once a week 4 = at least daily 9 = don't know/not applicable | 0 = not at all 1 = a little 2 = moderately 3 = very much 4 = extremely 9 = don't know/not applicable | 0 = not at all 1 = a little 2 = some 3 = a lot 4 = completely 9 = don't know |
| Being uncooperative when you try to help with bathing | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Being uncooperative when you try to help with toileting | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Being uncooperative when you try to help with eating | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Asking the same question over and over or repeating him or herself | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Seeking attention | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Screaming or hollering | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Generally disrupting activities | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |

| Have you had problems in the past six months with the client: | How often does the behavior occur? | How much does the behavior bother you as a caregiver? | To what degree do you think that the client can control his or her behavior? |
|--|--|---|---|
| | 0 = has never occurred 1 = has occurred before, but not in the past week 2 = once a week 3 = more than once a week 4 = at least daily 9 = don't know/not applicable | 0 = not at all 1 = a little 2 = moderately 3 = very much 4 = extremely 9 = don't know/not applicable | 0 = not at all 1 = a little 2 = some 3 = a lot 4 = completely 9 = don't know |
| Waking you or other family members up at night | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Wandering off | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Pacing | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Misbehaving in public so that you can't go out with him or her | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Misbehaving when you want to go out without him or her | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Being verbally aggressive or abusive to you or others | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Being physically aggressive to you or others | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Destroying property | 0 1 2 3 4 9 | 0 1 2 3 4 9 | 0 1 2 3 4 9 |
| Being sexually inappropriate | | | |